

# Rhode Island Resource Guide for Families of Children who are Deaf or Hard of Hearing



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OFFICE OF FAMILIES RAISING CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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APRIL 2006

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MAKE HE<sup>♥</sup>ALTH PART OF YOUR FAMILY  
RHODE ISLAND DEPARTMENT OF HEALTH

*The purpose of this guide is to provide families with current information and resources about health and educational options for children from birth through age 21 who have hearing loss. The Rhode Island Department of Health, Office of Families Raising Children With Special Health Care Needs does not endorse any particular intervention or educational model. To our knowledge, the resources listed are current and accurate as of April 2006. Inclusion of a resource does not reflect a recommendation; omission of a resource is not intentional. The information is provided so that you, the parent or caregiver, can make educated decisions for your child.*

# Dear Parents,

Learning that your child is deaf or hard of hearing can be difficult for you as a parent.

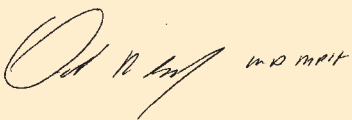
One of your first concerns may be how this will affect your child's future. You may also want to know what you should do to make sure that your child receives all the opportunities you want for him or her. There are new technologies, medical advances, and many community services and supports available to help you on this journey with your child.

You are not alone. Each year in the United States, about 12,000 babies are born with hearing loss. Ninety percent of these children are born to parents with normal hearing. You are your child's greatest advocate. Remember that children who are deaf or hard of hearing are limited only if they are viewed as having limitations.

The Rhode Island Resource Guide for Families of Children who are Deaf or Hard of Hearing was created in response to requests from families for information and resources about hearing loss to help them understand their child's growth, development, and educational options.

The Office of Families Raising Children with Special Health Care Needs of the Division of Family Health is dedicated to providing families of children with special health care needs with support, guidance, and encouragement regarding their children's care. We recognize the role of families as partners with professionals in the health care of their children. Families are the most important care providers and advocates for their children, and our goal is to assist them in this role.

Sincerely,

A handwritten signature in black ink, appearing to read "David R. Gifford", with a stylized flourish at the end.

David R. Gifford, MD, MPH

Director, Rhode Island Department of Health







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# Answers to Families' Frequently Asked Questions



If you have just learned that your child is deaf or hard of hearing, you may be experiencing many different feelings and be unsure of where to turn. You may be wondering what the future will bring and wishing that there was some help for you and your child. You may want to know how you will communicate with your child.

Special services are available for you, your family, and your child, and you should begin looking for them as soon as possible. This is very important so that your child can get off to a good start in developing language.

Families often ask some of the following questions about parent support, communication, audiology, hearing aids, deafness, Early Intervention, and education when they first learn about their child's hearing loss. After each question and short answer is a list of agencies that might be able to respond to your question in more detail. Some of these agencies work with early childhood specialists who have experience in providing assistance to deaf or hard of hearing infants and their families. Contact information for these agencies can be found in the "Local and National Resources" section of this guide.

## QUESTIONS ABOUT PARENT SUPPORT

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### **ARE THERE MANY CHILDREN WITH HEARING LOSS OR AM I ALONE IN THIS?**

You are not alone. There are many children who are deaf or hard of hearing. Approximately one child out of every thousand is born deaf. Ninety percent of these children have parents who hear, so about 10% have parents who are deaf themselves. There are many different causes of hearing loss in children, such as illnesses during pregnancy, viruses, accidents, and heredity. The agencies listed below can help connect you with other parents of children who are deaf or hard of hearing.

Alexander Graham Bell Association for the Deaf, Inc.

American Society for Deaf Children

Clarke School for the Deaf, Center for Oral Education  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Laurent Clerc Center, Gallaudet University  
National Cued Speech Association  
Rhode Island Association of the Deaf  
Rhode Island Commission on the Deaf and Hard of Hearing

**ARE THERE ANY SUPPORT GROUPS FOR PARENTS OF INFANTS WHO ARE DEAF OR  
HARD OF HEARING?**

There are support groups available in Rhode Island that you can easily join. Some of these groups are held during the daytime, some are held in the evening. You can contact any of the organizations listed to find out where support programs are available.

Alexander Graham Bell Association for the Deaf, Inc.  
American Society for Deaf Children  
Clarke School for the Deaf, Center for Oral Education  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
National Cued Speech Association  
Rhode Island Association of the Deaf  
Rhode Island Parent Information Network

**WHAT DOES MY CHILD'S HEARING LOSS MEAN FOR HIS OR HER LANGUAGE AND  
SOCIAL DEVELOPMENT?**

Most parents have had no personal experience with hearing loss, so it is helpful to connect with people who can help you learn what you need to know. All children do not have the same kind of hearing loss. The effects of hearing loss vary from child to child. There are many resources to help you understand what your child can hear, and what it means for your child's language and social development.

Alexander Graham Bell Association for the Deaf, Inc.  
American Society for Deaf Children  
Clarke School for the Deaf, Center for Oral Education  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Rhode Island Commission on the Deaf and Hard of Hearing  
Rhode Island Hearing Assessment Program  
Rhode Island Hearing Center, Rhode Island School for the Deaf

## QUESTIONS ABOUT COMMUNICATION

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### **HOW CAN I UNDERSTAND MY CHILD'S EARLY ATTEMPTS TO COMMUNICATE WITH ME?**

Whether your child can hear or not, most infants will first communicate by making sounds, smiling, crying, and using gestures like reaching and looking. Parents recognize these behaviors as meaningful and reinforce these early attempts to communicate. Communicate with your child with your smiles, hugs, and facial expressions, and by looking at each other, looking at things together, and playing together.

Alexander Graham Bell Association for the Deaf, Inc.  
Auditory-Verbal International  
Clarke School for the Deaf, Center for Oral Education  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Helen Beebe Speech and Hearing Center  
Rhode Island Association of the Deaf

### **HOW DO I GET MY CHILD'S ATTENTION?**

There are several approaches you can try. Try calling your child's name using a normal tone of voice or tap your child gently on the shoulder and wait for a response. You can also move into your child's field of vision and wait for your child to look at you.

Alexander Graham Bell Association for the Deaf, Inc.  
American Society for Deaf Children  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Rhode Island Association of the Deaf  
Rhode Island Commission on the Deaf and Hard of Hearing





#### **WHEN CAN I COMMUNICATE WITH MY CHILD?**

Parents can begin to communicate with their child as soon as the child is born. It is important that parents continue communicating with their child the same way they had before hearing loss was diagnosed. It is very important to provide children who are deaf or hard of hearing with access to language. Specialized professionals who are knowledgeable about deafness and hearing loss can help your child develop language.

Alexander Graham Bell Association for the Deaf, Inc.  
American Society for Deaf Children  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Helen Beebe Speech and Hearing Center  
Rhode Island Association of the Deaf  
Rhode Island Commission on the Deaf and Hard of Hearing

#### **HOW WILL I BE ABLE TO COMMUNICATE WITH MY CHILD?**

Currently, there are various approaches for helping young children who are deaf or hard of hearing learn language. There are many choices you can make about ways to communicate with your child. There are agencies that can help you to make informed decisions as you go through this process.

Alexander Graham Bell Association for the Deaf, Inc.  
American Society for Deaf Children  
Auditory-Verbal International  
Clarke School for the Deaf, Center for Oral Education  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
National Cued Speech Association  
Rhode Island Association of the Deaf  
Rhode Island Commission on the Deaf and Hard of Hearing

#### **HOW CAN I TEACH MY CHILD TO SPEAK IF SHE CAN'T HEAR?**

Hearing children generally develop speech and spoken language naturally, without any conscious effort. The key for language development, whether it is spoken language or a visual language such as ASL, is for the child to be able to take in the language of the environment. Currently, there are various approaches for enabling young children who are deaf or hard of hearing to develop speech and language. Your child's audiologist, speech therapist, and the

organizations listed below can help you learn activities that promote speech and language development.

Alexander Graham Bell Association for the Deaf, Inc.  
Auditory-Verbal International  
Clarke School for the Deaf, Center for Oral Education  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Helen Beebe Speech and Hearing Center

**WHERE CAN I LEARN ABOUT COMMUNICATING IN EARLY SIGN LANGUAGE WITH MY CHILD?**

Several organizations can help you locate resources for early sign language development.

American Society for Deaf Children  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Rhode Island Association of the Deaf  
Rhode Island Commission on the Deaf and Hard of Hearing

**WHO DO I CONTACT TO TEACH SPEECH TO MY CHILD?**

Your child's audiologist or a speech language pathologist can help you identify resources to teach speech to your child.

Alexander Graham Bell Association for the Deaf, Inc.  
Auditory-Verbal International  
Clarke School for the Deaf, Center for Oral Education  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Helen Beebe Speech and Hearing Center  
National Cued Speech Association

#### **WHO CAN HELP ME DEVELOP MY CHILD'S LANGUAGE SKILLS?**

Children need language for thinking, learning, communicating, and developing relationships with parents, family, and others. Hearing loss may interfere with the natural development of language unless steps are taken to enable the child to learn language. The Family Guidance and Early Intervention Programs will help develop a plan for your child to address this important area of development.

Alexander Graham Bell Association for the Deaf, Inc.  
Auditory-Verbal International  
Clarke School for the Deaf, Center for Oral Education  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf

#### **WHERE CAN I LEARN AMERICAN SIGN LANGUAGE (ASL) SO I CAN HELP MY CHILD LEARN ASL?**

The Family Guidance Program offers family sign language classes that focus on how parents talk to their infant or toddler. The Rhode Island School for the Deaf also offers a sign language program for adults. Several local colleges and universities also offer ASL classes.

Bristol Community College  
Brown University  
Community College of Rhode Island  
Family Guidance Program, Rhode Island School for the Deaf  
Rhode Island Association of the Deaf  
Rhode Island Commission on the Deaf and Hard of Hearing  
Rhode Island School for the Deaf

#### **QUESTIONS ABOUT AUDIOLOGY**

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##### **WHERE CAN I GET MY CHILD'S HEARING TESTED?**

All children born in Rhode Island have their hearing screened after birth while they are still in the hospital. You can contact the Rhode Island Hearing Assessment Program or talk to your child's doctor about the screening results. You can also contact a licensed audiologist who has experience testing infants and toddlers.

Memorial Hospital of Rhode Island, Audiology Department  
Rhode Island Hearing Assessment Program  
Rhode Island Hospital, Audiology and Speech Pathology Department  
Rhode Island Commission on the Deaf and Hard of Hearing

#### **WHO DO I CONTACT FOR INFORMATION ABOUT A COCHLEAR IMPLANT?**

There are several agencies in Rhode Island that can refer you to hospitals in the New England area where cochlear implant surgery is done. Currently, there is no place in Rhode Island where young children can get cochlear implant surgery.

Cochlear Implant Association, Inc.

Early Intervention Program

Family Guidance Program, Rhode Island School for the Deaf

Memorial Hospital of Rhode Island, Audiology Department

Rhode Island Hearing Assessment Program

Rhode Island Hospital, Audiology and Speech Pathology Department

Rhode Island Commission on the Deaf and Hard of Hearing

#### **QUESTIONS ABOUT HEARING AIDS**

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##### **HOW CAN I KEEP MY CHILD'S HEARING AIDS IN HIS EARS?**

Many parents encounter this issue. There are a few things you can check. Always communicate concerns with your child's audiologist. Some hearing losses are progressive or fluctuating (see section 4 of this guide for more information about types of hearing loss). A properly fit hearing aid amplifies sound according to your child's hearing loss and may need to be adjusted accordingly over time.

On a regular basis, check the ear mold to make sure it is comfortable, and be sure your child does not have an ear infection. If your child is healthy and there is nothing wrong with the hearing aid, try putting the hearing aids in when the child is preoccupied and/or doing an activity that he or she enjoys. For example, some toddlers are more inclined to keep their hearing aids in during lunch, because their hands are occupied with finger food and they are enjoying their meal. You could try two-sided tape or huggies as well. You could also contact your audiologist, another parent, or a support group for more suggestions.

The more consistent a parent is in inserting the hearing aids, the more the infant or toddler will get used to them. As your child grows and develops, you will be able to discuss together when the hearing aid needs to be adjusted and why your child wants or does not want to wear them. Try not to worry if your child goes through a period in school when he or she feels self-conscious about having hearing aids. With support and self-confidence, your child will eventually be able to see the benefit of hearing aids and choose to wear them at the appropriate times.



Alexander Graham Bell Association for the Deaf, Inc.  
American Society for Deaf Children  
Clarke School for the Deaf, Center for Oral Education  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Rhode Island Hearing Assessment Program  
Rhode Island Hearing Center, Rhode Island School for the Deaf

**HOW DO I PAY FOR MY CHILD'S HEARING AIDS?**

Your audiologist and Early Intervention specialist will guide you. They will contact your health insurance company first. There are also several foundations and organizations that may help you find financial aid for purchasing hearing aids.

Alexander Graham Bell Association for the Deaf, Inc.  
American Society for Deaf Children  
Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Hear Now  
Miracle Ear Children's Foundation  
Rhode Island Commission on the Deaf and Hard of Hearing  
Rhode Island Department of Human Services  
Rhode Island Hearing Center, Rhode Island School for the Deaf  
Shriners of Rhode Island Charities Trust

**HOW SHOULD I CHECK MY CHILD'S HEARING AID TO MAKE SURE IT WORKS?**

There are a number of ways that you can check to make sure the hearing aid is working properly. It is important for parents to become familiar with how the hearing aid sounds so they will recognize when it needs to be repaired. Your child's audiologist can teach you how to check the hearing aid daily. During a home visit a staff member from the Family Guidance Program can also show you ways to check the hearing aid.

Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Rhode Island Hearing Assessment Program

**MY CHILD'S HEARING AIDS ARE ALWAYS BUZZING. HOW CAN I STOP THIS?**

Your child's ear mold may be loose and need to be readjusted, the ear mold may be too small and need to be replaced, or there could be a problem with the hearing aid. As your child grows, your child will need new ear molds. You can contact your child's audiologist to have new ear molds made or to have your child's hearing aid checked.

Rhode Island Hearing Assessment Program

Rhode Island Hearing Center, Rhode Island School for the Deaf

**WHERE CAN I PURCHASE HEARING AID BATTERIES?**

Batteries can be purchased in drug stores, at audiology clinics, through hearing aid dealers, or at department stores.

Rhode Island Hearing Assessment Program

Rhode Island Hearing Center, Rhode Island School for the Deaf

**CAN I DONATE MY CHILD'S HEARING AIDS WHEN THEY ARE NO LONGER BEING USED?**

There are several agencies that collect used hearing aids, repair them, and loan them out to other children. Loaner hearing aids can be useful when a child's hearing aid is being repaired.

Memorial Hospital of Rhode Island, Audiology Department

People Actively Reaching Independence

Rhode Island Hearing Assessment Program

Rhode Island Hearing Center, Rhode Island School for the Deaf

Rhode Island Hospital, Audiology and Speech Pathology Department

Self Help for the Hard of Hearing

**QUESTIONS ABOUT DEAFNESS**

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**WHERE CAN I MEET DEAF ADULTS?**

You can contact the Commission on the Deaf and Hard of Hearing or the Rhode Island Association of the Deaf to get a calendar of events where you can meet Deaf adults in a social environment.

Rhode Island Association of the Deaf

Rhode Island Commission on the Deaf and Hard of Hearing

**WHERE CAN I FIND HELP ACCESSING ASSISTIVE DEVICES?**

Your child's audiologist, TechACCESS of Rhode Island, and Early Intervention are among the resources that can help you find assistive devices.

Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Rhode Island Association of the Deaf  
Rhode Island Commission on the Deaf and Hard of Hearing  
Sargent Rehabilitation Center  
Self Help for the Hard of Hearing  
TechACCESS of Rhode Island

**WHERE CAN I GET CAPTIONED VIDEOTAPES?**

The National Association for the Deaf provides free loans of educational and entertainment open-captioned cd-roms and videos for people who are deaf or hard of hearing.

Captioned Media Program  
Rhode Island Commission on the Deaf and Hard of Hearing

**WILL MY CHILD LEARN TO DRIVE?**

Statistics have shown that people who are deaf or hard of hearing are among the safest drivers on the road. Special accommodations, which may be needed for the driver's test, can be accessed through one of the agencies listed below.

Rhode Island Commission on the Deaf and Hard of Hearing  
Rhode Island Parent Information Network

**QUESTIONS ABOUT EARLY INTERVENTION**

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Early Intervention (EI) provides services to children with developmental delays from birth through age three and their families, including children who are deaf or hard of hearing. EI works with a statewide network of professionals who are skilled in working with children who are deaf or hard of hearing and their families.

**DO I HAVE TO PAY FOR EARLY INTERVENTION?**

EI is available for all eligible children from birth through age three regardless of ability to pay. EI services are provided at no direct cost to the family. EI will seek Medicaid, RIte Care, and private health insurance reimbursement when available.

Early Intervention Program  
Family Guidance Program, Rhode Island School for the Deaf  
Rhode Island Department of Human Services

**WHAT IS AN IFSP? WHO WRITES IT?**

An Individualized Family Service Plan (IFSP) is a comprehensive plan detailing the services your child will receive based on his or her needs. The parents and other professionals work together to set goals for your child and family and put the plan together.

Early Intervention Program

Family Guidance Program, Rhode Island School for the Deaf

**WHAT IS SERVICE COORDINATION?**

EI services are coordinated for each family through a partnership between families and professionals. These professionals can include a speech pathologist, audiologist, teacher of the Deaf, and others.

Early Intervention Program

Family Guidance Program, Rhode Island School for the Deaf

**QUESTIONS ABOUT EDUCATION**

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**WHAT WILL MY CHILD'S EDUCATION BE LIKE?**

While your child is under age three, your child can participate in the Family Guidance and Early Intervention Programs. When your child turns three, he or she will be eligible for special educational services through your local school system.

Early Intervention Program

Family Guidance Program, Rhode Island School for the Deaf

Rhode Island Department of Education

Rhode Island School for the Deaf

**WHERE CAN I GO FOR LEGAL ADVICE IF I FEEL MY CHILD IS BEING DISCRIMINATED AGAINST?**

You can contact a parent support group, an attorney, or one of the resources listed below.

Governor's Commission on Disabilities

Rhode Island Association of the Deaf

Rhode Island Commission on the Deaf and Hard of Hearing

Rhode Island Disability Law Center

Rhode Island Parent Information Network



# EITAN'S STORY

BY LEE VILKER



*Two years ago, my wife, Ronitte, and I found out that our son, Eitan, had a hearing loss. He was four years old then. Looking back, it was one of the most difficult and painful times of our lives.*

*Both of us had dealt with illness and even death of family members in the past, but nothing can prepare you for the pain and shock of learning that something is wrong with your child. We are programmed to protect our children from all danger. It was simply unimaginable to us that our child could have a disability that would likely impact the rest of his life.*

*It is difficult for even the best experts to diagnose certain types of hearing loss in children. My advice to anyone going through the diagnosis period is to listen to your gut. You know your child better than anyone else, and if you suspect something is wrong, you're probably right. Don't stop pursuing the issue until you are satisfied that the right conclusion has been reached.*

*I am a federal prosecutor who makes a living being tough – or at least appearing so – to career criminals. Yet for months after learning that my son had a hearing loss and needed hearing aids, I was unable to hold back my tears and broke down in front of strangers. But, this period somehow ended. My wife and I reached a level of acceptance that I didn't think was possible. The pain that accompanied the knowledge that our child had a disability gradually diminished, although it never disappeared.*

*For anyone going through this now, please know it will get better. You will realize that our sense of hearing, though significant, represents just one small piece in the total picture of who we are. Your child is still wonderful. You are still going to receive so much joy from him or her. And your child's life is not ruined. It just feels that way now. But that feeling will end.*

*At the time, everyone was telling me that things could be worse, we'll get through it, and Eitan will be fine. I can't tell you how little those words helped me at the time. Yet that is what I am trying to tell you now. You have to get through the first few months, and then you'll see that everything really is okay.*

*What helps you get through it is realizing how amazing your child is. He or she will adjust one hundred times faster than you will. You will see him or her happy, playing with friends, and going on with his or her life as if nothing has changed. All the important things are just as they were before. Your kid is great and the two of you love each other more than words can express. It just takes time to get to that point. You can't rush it. But you will get there.*



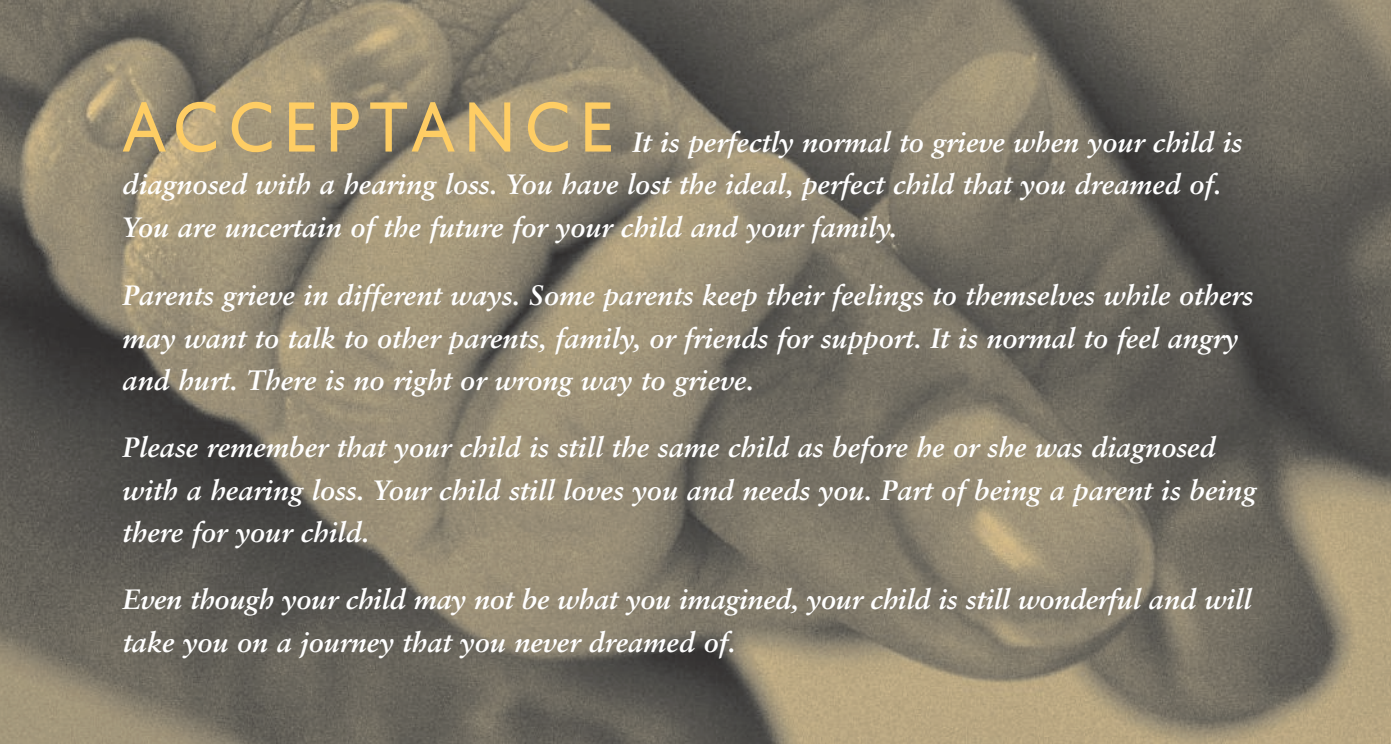
# Learning that your child is deaf or hard of hearing

## HEARING SCREENING FOR NEWBORNS

Learning that your child is deaf or hard of hearing can be overwhelming. Although all newborn babies are screened for hearing loss, children can develop a hearing loss at any stage in life. Depending on your child's age, he or she may have been diagnosed by the methods described in this section.

In 1993, Rhode Island became the first state in the nation to mandate hearing screening for all newborn babies under the Universal Newborn Hearing Screening Program. Since then, the Rhode Island Hearing Assessment Program (RIHAP) has provided hearing screenings for every infant born in Rhode Island. All birthing hospitals in Rhode Island participate in this program. For more information about the Universal Newborn Hearing Screening Program in Rhode Island, visit [www.infanthearing.org/legislative/summary/rhodeisland.html](http://www.infanthearing.org/legislative/summary/rhodeisland.html).

WHAT LIES BEHIND US AND  
WHAT LIES AHEAD OF US ARE TINY MATTERS  
COMPARED TO WHAT LIVES WITHIN US.  
~ RALPH WALDO EMERSON



**ACCEPTANCE** *It is perfectly normal to grieve when your child is diagnosed with a hearing loss. You have lost the ideal, perfect child that you dreamed of. You are uncertain of the future for your child and your family.*

*Parents grieve in different ways. Some parents keep their feelings to themselves while others may want to talk to other parents, family, or friends for support. It is normal to feel angry and hurt. There is no right or wrong way to grieve.*

*Please remember that your child is still the same child as before he or she was diagnosed with a hearing loss. Your child still loves you and needs you. Part of being a parent is being there for your child.*

*Even though your child may not be what you imagined, your child is still wonderful and will take you on a journey that you never dreamed of.*

A trained nurse or a skilled screener performs the hearing screening in the nursery before your baby leaves the hospital using one or two methods (described below). The screening does not hurt the baby and usually takes anywhere from less than 10 minutes to 30 minutes. All results are reviewed and interpreted by an audiologist (trained hearing specialist) and become part of your baby's medical record. If the results are unclear and the screening tests need to be repeated, you will be notified by a member of the RIHAP staff within one month after discharge. You may also get a call if the audiologist recommends further testing. Your child's doctor may also be notified.

The methods used to screen newborns in the hospital include Otoacoustic Emissions (OAE) and Automated Auditory Brainstem Response (AABR).

#### **OTOACOUSTIC EMISSIONS**

The most common screening method for newborns is called Otoacoustic Emissions (OAE). A probe with a tiny microphone and earphone is placed in the baby's ear. The earphone gives off a series of quiet clicks. If the baby's cochlea (hearing organ located in the inner ear) is healthy and free of fluid, it will produce an echo, which is picked up by the microphone. When a baby has hearing loss or excess fluid in the ear, no echo can be measured. If the baby passes the OAE, the screening is over. If the baby does not pass the OAE, a second screening method, called the Automated Auditory Brainstem Response, is used.

#### **AUTOMATED AUDITORY BRAINSTEM RESPONSE**

Another screening method, Automated Auditory Brainstem Response (AABR), uses small band-aid like sensors placed on the baby's head. Sound is then introduced to the ear(s) using small earmuffs. The sensors pick up responses from the hearing nerve and display them on a computer screen. This method usually lasts less than 15 minutes. If the baby does not pass this test, further tests are necessary to determine whether there is an actual hearing loss.

#### **OTHER DIAGNOSTIC TESTS**

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Even if your child passed the newborn screening tests at the hospital, he or she may have developed a hearing loss after the newborn period. There are tests that audiologists use to diagnose hearing loss in children. The type of test used depends on the age of your child and the type of information that the audiologist needs to check your child's hearing. These tests are not painful for your child.

#### **AUDITORY BRAINSTEM RESPONSE**

The Auditory Brainstem Response (ABR) is a diagnostic test similar to AABR, but it gives more detailed information about the amount of hearing loss in both ears and the effect the

hearing loss will have on the child’s ability to communicate. Using this method, an audiologist is also able to determine the type of hearing loss (see section 4 of this guide, “Causes and Types of Hearing Loss,” for types of hearing loss), if any, that your child has. In children older than six months, sedation (having the child be asleep) may be required in order for this test to be completed successfully, as it may take up to three hours.

**BEHAVIORAL TESTS: VISUAL REINFORCEMENT AUDIOMETRY  
AND CONDITIONED PLAY AUDIOMETRY**

These are hearing evaluations used with children who are old enough to respond to sounds either by turning their head or by playing a simple game, such as dropping a block into a container. Behavioral tests measure the amount of hearing loss and can help in locating the problem, whether in the middle ear, inner ear, auditory nerve, or some combination. Behavioral tests also provide information about how the hearing loss will affect your child’s ability to communicate. Behavioral testing sometimes indicates that hearing aids may help a child.

**OVERVIEW OF THE HEARING SCREENING  
AND REFERRAL PROCESS FOR YOUR DEAF  
OR HARD OF HEARING CHILD**

RIHAP Screens Newborns at Birth

RIHAP Re-screens Infants if Necessary



RIHAP Refers Child to an Audiologist



Audiologist Diagnoses Hearing Loss

Audiologist May Order Hearing Aids



Audiologist May Refer Child to:

» Early Intervention Program

» Family Guidance Program

» Speech Therapist

» Sign Language Therapist

» Ear, Nose, and Throat Doctor

» Otologist

» Genetic Counselor

**TYMPANOMETRY**

Tympanometry is used to test if your child’s middle ear is working normally. During the test, a small probe is placed in the child’s ear, and the air pressure is gently changed. If the middle ear is clear, the eardrum will gently move away from the probe and then return to normal. If there is fluid in the middle ear, the eardrum will not move. The results are presented in a diagram called a tympanogram.

**ACOUSTIC REFLEXES**

Typically, muscles in the middle ear contract in response to loud noises. When a child has normal hearing, these muscle contractions, called acoustic reflexes, are present. However, a child with a hearing loss or middle ear fluid may not have these reflexes. Acoustic reflexes are tested with a probe placed in the child’s ear. The probe makes beeping sounds in order to produce acoustic reflexes.



# A FAMILY'S STORY

Steve and Michelle, both profoundly deaf, had their first son, Kyle, in July 2004. They learned of his deafness after he failed the newborn hearing screening at Kent Hospital. Soon after, he had a follow-up appointment with an audiologist at the Rhode Island Hearing Assessment Program (RIHAP) where his hearing loss was confirmed. The whole family benefits from resources provided by the Rhode Island Commission on the Deaf and Hard of Hearing, the Rhode Island School for the Deaf Family Guidance Program, and Early Intervention services in Warwick. Early Intervention provides a sign language interpreter to Kyle in his daycare setting. The sign language interpreter has helped Kyle develop a large vocabulary of signs. In January 2006, the family welcomed a new addition, Luke Christopher. He failed the newborn hearing screening at Kent Hospital and will have a follow up appointment with an audiologist at RIHAP. The whole family uses American Sign Language as their primary language in the home.





In addition to your child’s pediatrician or primary care provider, there are many different types of professionals and resources that your family may use if your child does not pass a hearing screening test. Rhode Island uses a team approach, where specialists work together to provide care and resources for your child. You may also want to meet and interact with other families who have children with hearing loss.



Families provide each other with valuable information and support. Below is an explanation of the different types of professionals and resources who may work with you and your child.

## AUDIOLOGISTS

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Audiologists are professionals who specialize in hearing loss. They perform testing and help you understand the test results. Audiologists are not medical doctors

### **RIHAP AUDIOLOGIST**

All newborn hearing screening results are reviewed and interpreted by an audiologist from the Rhode Island Hearing Assessment Program (RIHAP). For those babies who do not pass the newborn hearing screening, the RIHAP audiologist contacts the families to schedule a repeat test when the baby is two to four weeks old. The RIHAP audiologist also helps families find follow-up services, such as pediatric audiologists who will help provide ongoing care. If further testing is needed, the RIHAP audiologist will refer your child to a community audiologist.

### **AUDIOLOGIST WITH PEDIATRIC EXPERTISE**

Children with hearing loss are referred by a RIHAP audiologist or their doctor to an audiologist with pediatric expertise for diagnosis. In Rhode Island, parents can choose from a list of audiologists that includes hospital-based or private practice audiologists. The audiologist conducts additional age-appropriate hearing tests to identify your child’s degree and type of hearing loss and recommends treatment such as hearing aids. In addition, the audiologist provides audiological counseling and follow-up treatment. In Rhode Island, with family permission, audiologists refer a child with a hearing loss to both Early Intervention and the Family Guidance Program (see section 3 of this guide, “Language, Learning, and Education,” for more information about these programs).

## OTHER PROFESSIONALS

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After your child has been diagnosed with a hearing loss, he or she may be referred by the audiologist to other professionals and support programs. The following information provides a description of the services you and your child may receive through these referrals.

### **OTOLARYNGOLOGIST (EAR, NOSE, AND THROAT DOCTOR)**

An Ear, Nose, and Throat (ENT) doctor specializes in diseases of the ear, nose, and throat. An ENT must examine a child to rule out any medical problems before parents purchase hearing aids. Your child may also see an ENT on a regular basis for treatment of ear infections.

### **SPEECH-LANGUAGE PATHOLOGIST**

A speech-language pathologist is a specialist who will evaluate your child's speech and language development. He or she can also evaluate your child's educational setting to ensure that your child can develop language skills. This specialist may also provide therapy and training to help your child learn speech and language.

### **OTOLOGIST**

An otologist works with other specialists on a cochlear implant team to determine if a cochlear implant is an appropriate treatment for a child. A cochlear implant is an electronic device that is surgically implanted behind the ear to maximize what hearing the child does have. If the team determines that your child is a candidate for a cochlear implant, and you decide that your child should have a cochlear implant, the otologist is the doctor who will perform the implant surgery.

### **GENETIC COUNSELOR**

A genetic counselor is a specialist in the field of inherited diseases. Sometimes genes for hearing loss are passed from parents to their children, even if the parents don't have a hearing loss. This specialist can provide genetic testing that identifies the genes that are linked to some types of hearing loss. If you are considering genetic testing, the genetic counselor will talk to you about testing options, review the test results, help you make treatment decisions, and connect you to community resources when needed.

## SUPPORT PROGRAMS

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Children with special health care needs are those who have, or are at risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require more health services than children generally do. Children with hearing loss are considered to have special health care needs. Rhode Island has several programs designed for children with special health care needs. For example, all infants who are diagnosed with hearing loss are referred by their

audiologist to both Early Intervention and the Family Guidance Program. In Rhode Island, all babies are referred for services as early as one month of age. It is critical that families get accurate and clear information about the support programs available and the services they provide to benefit their child's development.

#### **EARLY INTERVENTION PROGRAM**

The Early Intervention Program (EI) is a family-centered program that promotes the growth and development of children with developmental delays from birth to three years of age. Premature newborns who are at risk for hearing loss are also at risk for developmental delay. A developmental delay occurs when a child does not develop skills, such as crawling and talking, by an expected age. Hearing loss may impact a child's language development.

EI can help connect families to professionals who understand hearing loss and can help a child's sign and/or speech and language development. The program provides an initial assessment of your child's development, in-home support, links to resources in the community, and services to help your child transition into preschool, if appropriate. More information about EI is provided in section 3 of this guide, "Language, Learning, and Education" (see section 9 of this guide, "Local Resources," for contact information).





## **FAMILY GUIDANCE PROGRAM**

The Family Guidance Program (FGP), located at the Rhode Island School for the Deaf, is designed specifically for infants and children with hearing loss and their families. Its staff of family educators has specialized knowledge and experience in the field of deafness and hearing loss and its effect on communication.

Helping children with hearing loss is often different than helping other children who need special education. The FGP understands the emotions of families trying to make difficult decisions about their child's communication needs. The mission of the FGP is to provide families with guidance and information that will help them make decisions and advocate for their children. The FGP emphasizes the importance of helping families establish communication with their infant as soon as possible, and helps parents optimize both visual and/or auditory pathways for learning language.

Family educators offer a range of support and training tailored to the individual needs and choices of families. This includes helping families:

- » Understand information on infant hearing loss, which can be confusing and conflicting;
- » Recognize the best methods of communicating with their infant;
- » Make decisions about approaches to communicating;
- » Select appropriate amplification devices and technology to enhance early hearing experiences;
- » Identify their child's progress through in-depth observations and assessments designed specifically for deaf and hard of hearing children;
- » Connect to other families;
- » Make decisions about appropriate school placement in community environments or special programs at the age of three.

The Family Guidance Program offers the following services:

- » Home Visits – Home visits are scheduled as soon as the family requires support and chooses to participate. Family educators come to the family's home and observe how parents interact with their baby, point out the many positive things they already do with their baby, and suggest additional techniques to encourage listening, gesturing, babbling (first type of speech), watching, and learning.
- » Baby Group – Parents have an opportunity to meet other families and share experiences and strategies that worked for them.
- » Parent/Toddler Group – Families and children with hearing loss have an opportunity to interact with each other. Parents can also talk about the next steps, such as transition to school.

- » Parent Library – Books, resources, and videotapes about hearing loss, sign language, and child development are available for families to borrow and discuss with staff.
- » Assessment – The FGP assesses the language, speech, and auditory development of infants and toddlers and makes sure communication milestones are met in a timely fashion. Assessment information, including input from parents, is used to make recommendations about the family’s communication plan.

See section 9 of this guide, “Local Resources,” for contact information for the FGP.

#### **CEDARR FAMILY CENTERS**

CEDARR stands for Comprehensive, Evaluation, Diagnosis, Assessment, Referral, and Re-evaluation. CEDARR Family Centers can provide families of children with special health care needs with information, clinical expertise, connection to community supports, and assistance to help them meet their children’s needs. In Rhode Island, CEDARR Family Centers provide services in coordination with other programs that children may be participating in. Children can be referred to CEDARR by parents or guardians, doctors, Early Intervention programs, schools, community agencies, or other service providers.

The services available through CEDARR Family Centers include: basic services and supports, specialized clinical evaluations, Family Care Plan development, crisis intervention services, and family care coordination. CEDARR Family Centers will make referrals and help coordinate services and supports determined necessary for the child and family. This includes direct services if determined appropriate by the CEDARR Family Center. Direct services include: Home-Based Therapeutic Services (HBTS), Personal Assistant Services and Supports (PASS), and Kids Connect.

There are currently three CEDARR Family Centers in Rhode Island that serve families throughout the state. Families can choose whichever Center they prefer. CEDARR Family Center locations are listed in section 9 of this guide, “Local Resources.” For more information about CEDARR, contact the Rhode Island Department of Human Services listed in section 9 of this guide, “Local Resources.”

#### **MEDICAL ASSISTANCE PROGRAM**

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The Medical Assistance Program, also called Medicaid, is a federal and state program created by Congress in 1956 under the Social Security Act. Medicaid programs are jointly funded by the federal and state governments and are administered by each individual state. In Rhode Island, the Rhode Island Department of Human Services is the state agency responsible for administering the Medical Assistance Program.

Within Medicaid is a program for children from birth to age 21 called the Early and Periodic Screening Diagnosis and Treatment Program (EPSDT). Under this program, children must receive screening and diagnostic services as well as medically necessary treatments, which may not be available under the state's Medicaid plan but are allowed under federal Medicaid law. The EPSDT Program ensures that Medicaid benefits for children are the same across the delivery systems. More information about Medicaid is available through the following website: [www.cms.hhs.gov/medicaid](http://www.cms.hhs.gov/medicaid).

#### **MEDICAL ASSISTANCE ELIGIBILITY**

In Rhode Island, a child is eligible for Medicaid if he or she has medical coverage through any of the following: RItE Care, RItE Share, Supplemental Security Income (SSI), Katie Beckett, and Adoption Subsidy.

#### **RITE CARE**

RItE Care is Rhode Island's Medicaid managed care program that provides insurance coverage to families on the Family Independence Program, eligible uninsured pregnant women, and parents and children up to 19 years of age. Families receive most of their health care through one of the three participating health plans: Neighborhood Health Plan of Rhode Island, United Healthcare of New England, and Blue CHiP.

##### *Neighborhood Health Plan of Rhode Island*

299 Promenade Street

Providence, RI 02908

Phone: (401) 459-6000 or (800) 963-1001

Fax: (401) 459-6066

Website: [www.nhpri.org](http://www.nhpri.org)

##### *Blue Cross Blue Shield of Rhode Island*

444 Westminster Street

Providence, RI 02903

Phone: (401) 459-2000

Website: [www.bcbsri.com](http://www.bcbsri.com)

##### *United Healthcare of Rhode Island*

475 Kilvert Street

Warwick, RI 02886

Phone: (401) 737-6900

Website: [www.unitedhealthcare.com](http://www.unitedhealthcare.com)

**RITE SHARE**

RIte Share is a premium assistance program that helps low and middle-income families obtain health insurance coverage through their employer (or spouse's employer) by paying all or part of the employee's share of monthly premiums. Under the RIte Share Program, individuals who are income eligible for Medical Assistance and are employed by an employer who offers an approved health plan can enroll in their employer's health insurance plan. The RIte Share Program will also pay all or part of the co-payments associated with the employer's health plan.

*Rhode Island Department of Human Services*

Center for Child and Family Health

600 New London Avenue

Cranston, RI 02920

Information Line: (401) 462-5300 (English and Spanish)

TTY: (401) 462- 3363

RI Relay: 7-1-1

Website: [www.dhs.ri.gov](http://www.dhs.ri.gov)

**SUPPLEMENTAL SECURITY INCOME (SSI)**

Supplemental Security Income is a federal program that provides monthly cash benefits to individuals, including children birth to 18 years of age, with physical, developmental, and/or mental impairment that results in "marked and severe functional limitations." If a child is eligible for SSI benefits, he or she is also eligible to receive Medicaid Assistance benefits. Children under 18 years of age with a physical, developmental, and/or mental impairment may be eligible if their family also qualifies based on limited income and resources. After 18 years of age, SSI benefits are based only on the income of the individual applying for SSI.

*Social Security Office*

380 Westminster Street, Room 318

Providence, RI 02903

Phone: (401) 528- 4535 or (800) 772- 1213

Fax: (401) 528- 4698

Website: [www.ssa.gov](http://www.ssa.gov)

**KATIE BECKETT**

Katie Beckett is an eligibility provision that allows children under the age of 18 who have significant disabling conditions and live at home to receive Medical Assistance coverage. This enables children with disabilities to be cared for at home instead of in an institution. Level of Care Determination is required for eligibility – meaning that if the child were not living at

home with Medical Assistance benefits/coverage, he or she would require care and services in a hospital or institutional setting. The cost of care provided at home must be less than what Medical Assistance would pay if the child were in a hospital or other institutional setting. Only the child's income and resources (not the family's) are considered when determining eligibility for Katie Beckett.

*Rhode Island Department of Human Services*

Long Term Care

600 New London Avenue

Cranston, RI 02920

Information Line: (401) 462-5300 (English and Spanish)

TTY: (401) 462-3363

RI relay: 7-1-1

Website: [www.dhs.ri.gov](http://www.dhs.ri.gov)

**ADOPTION SUBSIDY**

Children in Adoption Subsidy may qualify for Medical Assistance. The Adoption Subsidy Program is administered through the Department of Children, Youth and Families (DCYF).

*Rhode Island Department of Children, Youth and Families*

Adoption Services Unit

101 Friendship Street

Providence, RI 02903

Phone: (401) 254- 7021

Website: [www.dcyf.ri.gov](http://www.dcyf.ri.gov)



# WELCOME TO HOLLAND

BY EMILY PERL KINGSLEY ~ *I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...*

*When you are going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.*

*After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."*

*"Holland?!?" you say, "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."*

*But there's been a change in flight plan. They've landed in Holland and there you must stay.*

*The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.*

*So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met.*

*It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.*

*But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."*

*The pain of that will never, ever go away, because the loss of that dream is a very significant loss.*

*But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.*



# Language, Learning, and Education

A family with a child who is deaf or hard of hearing will need to use a form of communication that everyone in the family can understand. Since every family is different, the decision about which communication method to use must be based on the needs of your child and your family. This decision will require commitment from the family and professionals on your child's team. All the communication methods described below prepare your child to go to school, work, and live in a hearing society.

**THERE ARE NO  
SEVEN WONDERS OF THE  
WORLD IN THE EYES OF A CHILD.  
THERE ARE SEVEN MILLION.  
~WALT STREIGHTIFF**

The level at which one child with moderate hearing loss successfully discriminates speech (tells the words apart) may be different for another child with moderate hearing loss. It is important for parents to keep this variability in mind, so they do not think they are doing something wrong if their child does not discriminate speech as well as another.

You should also get to know other parents of deaf children and deaf adults in the community. Family Voices at Rhode Island Parent Information Network can help put families in touch with other families (see section 9 of this guide, "Local Resources," for contact information).

## METHODS OF COMMUNICATION

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For every child with hearing loss, the family needs to decide if the child will communicate with an oral, manual, or combination of methods. Families and professionals must work together to choose a method that meets the needs of the child and the family.

### **AUDITORY-ORAL METHOD**

Auditory refers to the ears and hearing, and oral refers to the mouth and speaking. If your child has enough hearing to learn language from listening, this communication method may be an option. The auditory-oral method teaches a child to talk, use his or her hearing as much as possible, read lips, and use other clues like facial expressions and gestures to understand what people are saying. This communication method is also called oralism because it teaches a child how to talk and read lips. The use of hearing aids or cochlear implants is an important part of this method because the child will need to hear as much as possible.

#### **AUDITORY-VERBAL METHOD**

Auditory refers to the ears and hearing, and verbal refers to the mouth and words. If your child has enough hearing, and can use it well, this method may be an option. The auditory-verbal method teaches children to use whatever hearing they have to listen instead of reading lips. Little emphasis is placed on visual clues such as facial expressions or gestures. Weekly lessons with an auditory-verbal therapist are an important part of learning this method, as are hearing aids or cochlear implants. Parents participate in all therapy sessions and practice the same techniques at home.

Keep the following in mind when deciding if this is the right communication method for your child.

- » Starting early will give your child the most time to “exercise” his or her sense of hearing.
- » The sooner your child learns to listen, the more time he or she will have to practice before starting school.
- » The more your child can hear, the easier it will be for him or her to listen.

#### **BILINGUAL-BICULTURAL METHOD: AMERICAN SIGN LANGUAGE**

Bilingual means being able to use two languages. Bicultural means being a part of two cultures or two communities. The bilingual-biculturalism (bi-bi) method is based on the idea that deaf children need a language they can see because spoken language is very hard to learn without hearing. American Sign Language (ASL) is a language that uses a visual method of communication. With bi-bi, children learn ASL as their first language and English as their second language. ASL is their main way of communicating with others. English is used for writing and reading.

ASL is the language of the Deaf Culture and Deaf Community. Any idea that can be expressed in English can be completely expressed visually in ASL through placement, movement, and expression of the hands and face. In the Deaf Community, eyes and hands are valued above speaking because they are used in ASL and are the key to language. This method prepares children to function in the hearing world, but emphasis is placed on first developing visual language competency.

ASL is a complete language with its own grammar and language rules. Children born to Deaf parents learn ASL in the same way that hearing children learn spoken language from hearing parents. Deaf children of hearing parents tend to learn ASL from Deaf adults, from other Deaf children, and in family sign classes. Children who use ASL become part of Deaf Culture and the Deaf Community, yet they are still a part of their family’s culture and community. These children are truly bilingual and bicultural.



As for any adult learning a different language, it can be difficult for hearing parents to learn ASL quickly. There are many options for learning ASL, such as individualized lessons with Deaf adults, sign language classes, college-level sign language classes, videotapes, books, on-line resources, and family sign language classes that focus on how parents talk to their infant or toddler. Many of these classes and learning activities are available at the Family Guidance Program, Rhode Island School for the Deaf, Bristol Community College in Fall River, Brown University, and the Community College of Rhode Island. See section 9 of this guide, “Local Resources,” for contact information.

#### **CUED SPEECH**

Cued speech is a way to “see” spoken English. It was developed to teach deaf children how to read by seeing the sounds. Cued speech uses eight different hand shapes that go in one of four places around the face and are used together with speaking. Since many spoken words look exactly alike on the mouth, cues will allow the child to see the difference between them. For this method to work, both the speaker and the listener must know the system.

In the classroom, a cued speech translator can help a deaf child understand the teacher. The translator repeats the teacher’s words without sounds and uses cues to make the words clearer. The translator can also “speak” for your child when he or she cues back. Cued speech is not widely used in the United States today. It may be difficult to find a translator or someone to teach cued speech.

#### **TOTAL COMMUNICATION**

Total Communication (TC) encourages children with hearing loss to communicate using both hearing and seeing. A child who is taught to use TC will learn many of the skills used in other communication methods such as listening, sign language, lip reading, and cued speech. As a child’s skills develop, he or she may switch to another method. For example, a child may use sign language less often as he or she learns to speak. TC gives children the tools they need to understand others and to be understood at a very young age.

## DEAF CULTURE

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Deaf Culture includes the traditions, values, beliefs, heritage, social networks, political goals, artistic expressions, attitudes, and language that are particular to Deaf people. The Deaf Culture movement began in the 1970s. American Sign Language (ASL) is the language of the Deaf Community and is one of the most important aspects of Deaf Culture.

Deaf Culture is represented in plays, books, artwork, magazines, and movies targeted at Deaf audiences. There are many traditions that are an important part of Deaf Culture, such as:

- » Attending social gatherings including athletic events, community picnics, theatrical performances, conferences, and reunions
- » Belonging to local or national Deaf organizations
- » Naming someone using sign language that reflects something about that person
- » Storytelling using American Sign Language
- » Advocacy

The Deaf President Now movement at Gallaudet University in Washington, DC in 1988 was the height of the civil rights movement for Deaf adults and is an important part of Deaf Culture. More information is available at <http://clerccenter.gallaudet.edu/DPN/index.htm>.

It is helpful for Deaf children to learn about Deaf role models who have successful careers and lead fulfilling lives. Through these examples, Deaf children can understand that there are no limits to what they can achieve.

### **SIGNING WITH YOUR BABY (FROM WWW.SIGNINGBABY.COM)**

There are several advantages to signing with your baby. Infants taught sign language:

- » Can communicate wants and needs to their caregivers at an early age.
- » Will have an earlier understanding of the English language.
- » May learn to speak earlier.
- » Could have an above-average ability later in life to learn a new language.

Parents who sign with their baby may experience:

- » Lower frustration levels (for both you and your baby) because your baby can communicate with you.
- » Deeper bonding with your baby because you have greater insight into your baby's mind.
- » A higher level of trust from your baby because he or she knows that you understand what he or she is trying to tell you.
- » Satisfaction. What a great feeling it is to know that you can effectively communicate with your preverbal infant.

## GETTING AN EARLY START WITH LEARNING

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The sooner a child is diagnosed with hearing loss, the more chances he or she will have to learn language. All children under age three who are diagnosed with hearing loss are referred by their audiologist to Early Intervention. All children are also referred to the Family Guidance Program. A child's ability to learn language can be improved by these services, so it is important to get your child involved as soon as possible. The public education system can provide your child with the services he or she needs after age three.

### **EARLY INTERVENTION PROGRAM**

Early Intervention (EI) is a family-centered program that promotes the growth and development of infants and toddlers with developmental challenges. Early Intervention emphasizes the unique strengths of the child within the family unit. Early Intervention serves all eligible children (from birth to three years of age) and their families regardless of income or health insurance coverage. Participation in the Early Intervention Program is voluntary.

Each state is mandated to provide an Early Intervention Program for children with developmental delays (from birth to three years of age) in accordance with a federal law called the Individuals with Disabilities Education Act (IDEA). In Rhode Island, the Rhode Island Department of Human Services administers the Early Intervention Program.

### **PROGRAM REFERRAL**

Rhode Island has a Comprehensive Child Find System to ensure that all infants and toddlers in the state who are eligible for Early Intervention services are identified, located, and evaluated through universal screening and direct referrals. The Comprehensive Child Find System includes: Universal Screening, Direct Referrals, and Public Awareness.

All babies born in Rhode Island hospitals are screened at birth for specific congenital conditions and disorders under the Department of Health's Universal Newborn Screening Program. A follow-up in-home screening is offered through the Family Outreach Program (FOP) to families of children identified as "at risk" for developmental delays. The FOP program is administered by the Rhode Island Department of Health. Children in need of additional services are referred to Early Intervention.

Direct Referrals to Early Intervention can be made by family members, guardians, primary care physicians, and community agencies for infant and toddler screening, evaluation, and assessment to determine eligibility for services.

#### **PROGRAM ELIGIBILITY**

A child may be eligible for Early Intervention if he or she is under three years old and is experiencing developmental delays, has certain diagnosed conditions(s), or has circumstances that may result in significant developmental delays. A developmental delay occurs when a child does not develop certain skills by an expected age. Hearing loss may impact a child's language development.

When a child is referred to Early Intervention, eligibility will be determined through an evaluation and assessment performed by the Early Intervention Program. The purpose of the evaluation or assessment process includes not only eligibility determination, but also information gathering for planning purposes and answering family questions regarding their child's development.

#### **INDIVIDUALIZED FAMILY SERVICE PLAN**

After a child is determined eligible for Early Intervention, the family works with a team of EI professionals to design a plan called the Individualized Family Service Plan (IFSP). This plan outlines the child's strengths and needs based on the completed assessment and concerns of the family. The IFSP identifies the supports and services necessary for the child and family to meet desired goals. The IFSP is reviewed every six months or as needed. An EI Service Coordinator, assigned to every family, is responsible for coordinating services identified in the plan including those with other agencies. The Service Coordinator is the primary contact for the family while in Early Intervention.

#### **PROGRAM SERVICE DELIVERY**

Early Intervention services are provided by a team of certified professionals. Every EI provider site also has at least one parent consultant available to help families. Parent consultants are family members of children with special health care needs who have participated in Early Intervention. Their role is to help families understand their child's health care services and to provide support, resources, and connections to other families.

Early Intervention services are provided in "natural environments." Natural environments are the day-to-day settings, routines, and activities within which young children learn best. Services provided in natural settings allow parent(s) and caregivers to be involved in the child's activities throughout the day with the service providers acting as consultants, teachers, and coaches.

EI services are provided in a number of locations throughout Rhode Island. Families can choose the provider site that best meets the needs of their child and family. Rhode Island's Early Intervention providers are listed in section 9 of this guide, "Local Resources." For more



information about EI, go to [www.dhr.ri.gov](http://www.dhr.ri.gov) or contact the Department of Human Services (see “Local Resources” for contact information).

#### **FAMILY GUIDANCE PROGRAM**

The child’s audiologist, EI provider, pediatrician, or other professional can refer the child to the Family Guidance Program. The Family Guidance Program at the Rhode Island School for the Deaf provides support, guidance, and information to families of children who are deaf or hard of hearing. Family Guidance Program staff work in partnership with EI staff to address the family’s needs. As with EI, it is the family’s choice to participate in the Family Guidance Program. More information about the Family Guidance Program is provided in section 2 of this guide, “Learning That Your Child is Deaf or Hard of Hearing.” Contact information is provided in section 9 of this guide, “Local Resources.”

#### **FROM EARLY INTERVENTION TO SPECIAL EDUCATION**

According to the Individuals with Disabilities Education Act (IDEA), deafness and hearing loss are categories of disability. As a result of this law, your child may transition from EI to preschool special education services by age three. Children who are deaf or hard of hearing are eligible for special education services through the public school system in your city or town from age 3 through 21.

All children must complete an evaluation with the local school district in order to be eligible for special education services. When your child is 28 months old, your EI service coordinator will ask you to sign a release to allow a special education representative to contact you about this evaluation. When your child is 30 months old, your local school department will schedule a meeting to plan for your child’s transition from EI to special education services. The EI representative and you will be asked to attend this meeting. You may also want to include other members of your child’s team in this meeting, such as the audiologist, speech/language specialist, or anyone else involved in your child’s care.

If your child is between 3 and 21 years of age, your child’s doctor, community-based agencies, day care providers, or you can also initiate a referral for a special education evaluation by contacting the special education department of your local school district.

#### TIPS FOR FAMILIES: THE IEP MEETING

- » Bring a friend or family member to the meeting with you. It helps to have another person there to listen and take notes.
- » Go to the meeting prepared. Take information about your child's strengths and needs, what you see at home or in other settings.
- » Carry written information in a folder or notebook.
- » The image that you project can make a difference. Dress neatly and appropriately.
- » Arrive on time. Arriving on time shows that you feel this is an important meeting and that you are ready to conduct business.
- » Shake hands and acknowledge other people at the meeting as you are introduced to them. If no one begins the introductions, begin by introducing yourself.
- » Sit with the other team members. Remember that you are a part of the decision making process.
- » Speak clearly and look at other team members while talking.
- » Make positive statements such as "I expect...", "I understand...", "My child needs...", "I am concerned that...", "I want to cooperate with you, however, I am concerned that...", "I know that you have many children to care for..."
- » Ask questions and for clarification of anything that you do not understand.
- » Remain as friendly as possible. Separate the people from the problems. Keep your emotions in control.
- » Focus on the issues at hand. Do not be sidetracked by other issues, such as past experiences, lack of available funding, or what "all the other children" are doing.
- » Make your proposal and expect to get what your child needs. Be flexible enough to accept minor revisions, but be firm about the major issues.
- » Feel confident enough to end the meeting if it seems that no more progress can be made. Tell the other teammembers that you would like to continue working with them, and set up another appointment for a fresh start.
- » Sometimes necessary team members begin leaving the meeting before decisions have been made. If this happens, stop the meeting and reschedule a time when all team members can attend and finish negotiations.
- » Follow up with a letter to the person who ran the meeting. If you are satisfied, state what the agreements were. If you are not satisfied, explain your position, your understanding of their position, the next course of action, and your timelines.
- » Remember that you are advocating for the safety, health, well-being, and future of your child. If you do not do it, who will?

*Courtesy of the Rhode Island Parent Information Network, Adapted from The Network News*







## SPECIAL EDUCATION

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Special Education programs operate in all Rhode Island school districts to provide specially designed instruction to meet the unique needs of each child with a disability. The Rhode Island Department of Education (RIDE) is the state agency responsible for monitoring these services, which are free for families.

Once it is determined that a child with hearing loss is eligible for special education services, these services will be determined by a team including you, as a parent, a school district representative, special and general education teachers, and others with expertise about your child's unique needs and strengths. The team will record its decisions in a written Individualized Education Program (IEP). The IEP identifies your child's individual strengths and needs and determines goals, accommodations, assistive technology, and other supports your child will need. These supports may include special education, speech-language therapy, audiology services, occupational therapy, medical services, school health services, transportation, recreation, counseling, or other services. Information included in the IEP for older children will address planning for transition from school to higher education, employment, and adult life.

IEP meetings will be held at least once a year (or more if necessary) to review and revise your child's program. IEP meetings can include regular and special education teachers, community providers (the child's physician or therapist, for example), a parent, and anyone else at the parent's request.

In order to create a comprehensive IEP for your child, it is important to work closely with the other team members and share your thoughts about your child's educational needs. You know your child best, and your concerns and knowledge are important to creating an effective plan.

Parents and school personnel may find that they cannot reach agreement about a child's IEP. There are ways for parents and the school to resolve disagreements through mediation or due process hearings with RIDE.

- » Mediation involves a meeting with the parent, the school department, and an impartial third person, called a mediator, to talk openly about the disagreement and try to reach an agreement that all participants can support.
- » Due process requires the parent and the school department to present evidence to an impartial third party, called a hearing officer, who will decide how to resolve the issue.
- » In a situation where you believe that the school district appears to have proceeded in violation of your child's rights under special education law, you have the right to file a



special education complaint with RIDE. Filing a complaint requires the parent to fill out forms that are available by contacting the Office of Special Populations at RIDE. Complaints will be investigated and addressed within 60 days.

Children who are not eligible for special education services may be assisted through rights outlined in Section 504 of the Rehabilitation Act of 1973. This law prohibits discrimination on the basis of a disability in programs and activities that receive federal financial assistance. Children with disabilities can receive related services under Section 504 to provide them with an “appropriate education,” described in writing in a 504 plan, even if they are not receiving special education services. An “appropriate education” means an education that is comparable to one provided to students who do not have disabilities. For more information, visit the U.S. Department of Education website at [www.ed.gov](http://www.ed.gov).

## EDUCATIONAL PLACEMENTS

When it comes to making decisions about your child’s education, it is important to explore the options and talk with professionals. If you are not satisfied with the educational setting in

READING TO YOUR DEAF OR HARD OF HEARING CHILD
It is important to read to your child and nurture his or her ability to write when the time is appropriate.
TIPS FOR READING TO YOUR DEAF OR HARD OF HEARING CHILD
» Choose books both you and your child will enjoy together.
» Make sure your child sees your face, your signs, and the printed words at the same time.
» Don’t be limited by the words. Expand on the book’s ideas.
» Be dramatic. Play with the signs and exaggerate your facial expressions and movements to show different characters.
» Talk about the story as you read. Ask your child questions and link ideas in the story with your experiences. Have your child guess what will happen next.
» Keep your child’s attention by gently tapping on his or her shoulder or by giving a gentle nudge.
» Change the locations where you use sign language. Sometimes sign on the page; sometimes sign on the child; sometimes sign in the usual place.
» Keep a pad or paper nearby so you can sketch an idea or a cue for your child.
» Read the story over and over if your child asks. This is an important part of your child’s language development.
» Act out the story after you are finished reading.

your local school district, the first step in discussing alternatives is to request that the school district reconvene the IEP team to review and reconsider your child's plan. The laws about education are designed so that families can re-evaluate their child's educational setting and make appropriate changes with help from the IEP team.

The following questions may be helpful for families to ask while learning about an educational setting:

- » What are the school's expectations for a student with hearing loss?
- » If it is a program for the Deaf, are there opportunities to interact with hearing peers?
- » How much experience does the staff have educating students with special needs?
- » What is the school's policy about classroom observations by parents and other team members?
- » Is the staff willing to work with professionals from a different facility?
- » Will all of the child's needs be met at the school?
- » Does the school offer a variety of therapies like speech, occupational, and sign language therapy?

You may hear the following terms about educational placements at your child's IEP meeting.

#### **INCLUSION**

Inclusion means that the deaf or hard of hearing student attends classes with hearing peers, usually in their home school district. The school provides appropriate support services that help the child succeed in school. Some students may need a lot of support, and others may need less. Support services may include speech and language therapy, acoustical accommodations, educational audiological consultation, assistive listening systems, interpreters, note-takers, curriculum and test-taking accommodations, resource services, or physical or occupational therapies. Children who are educated in an inclusionary setting usually communicate with spoken language, an English-based sign language, or cued speech.

#### **SELF-CONTAINED CLASSROOM**

A self-contained classroom is made up of students with hearing loss or other special needs who are taught by a Teacher of the Deaf or special educator. Oftentimes, the class is within a public school with typically hearing children. Children educated in this setting may communicate with spoken language, cued speech, or sign language.

#### **PARTIALLY INCLUDED**

A partially included student spends part of the day in an inclusionary setting and part of the day in a self-contained classroom.

## THE RHODE ISLAND SCHOOL FOR THE DEAF (RISD)

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RISD offers educational programs to deaf and hard of hearing students and their families. The School's early intervention, preschool, elementary, and junior and senior high school programs educate deaf and hard of hearing students from birth through high school.

### **OUTREACH SERVICES**

RISD provides Outreach Services to deaf and hard of hearing children in typical classrooms throughout the state. Outreach Services include:

- » Diagnostic assessment
- » Placement evaluation
- » Monitoring of academic progress
- » Support groups for students and their families

In addition, RISD provides the following services for teachers and staff:

- » Education and training for teachers and support staff working with deaf and hard of hearing students in their classrooms
- » Training for Special Education Directors and their staff about assistive technology and interpreters

RISD recognizes the challenges that many deaf and hard of hearing children experience in schools. Efforts are made to connect these students and their families with others through group meetings, summer camps, and informal get-togethers. Hearing students often visit their friends at RISD and join them for social activities, dramatic presentations, and athletic events.

### **INTEGRATED PROGRAMS**

RISD students benefit from interaction with hearing children and adults in preparation for participation in the greater Rhode Island community. RISD encourages parents to involve their children in a variety of community-based programs at a very early age. RISD pre-school and early elementary classes often work with students and teachers from other schools on projects. As students grow, they are offered more formal academic and vocational programs to supplement their course work.

### **COMMUNITY PREPARATORY SCHOOL, PROVIDENCE**

RISD and Community Preparatory School work together to integrate deaf and hard of hearing students into classes with hearing students. RISD helps ensure that students have the support services they need to take advantage of Community Preparatory School's rigorous academic program in grades four through eight.

#### **EAST PROVIDENCE HIGH SCHOOL AND EAST PROVIDENCE CAREER TECHNICAL CENTER**

Academic and vocational opportunities are offered to high school students at East Providence High School and East Providence Career Technical Center. Students from different communities learn together in small groups, using resources coordinated by RISD, involving teachers, interpreters, and tutors.

#### **SHARED PROGRAMS WITH THE LOCAL COMMUNITY**

Some students chose to be integrated into schools in their own communities. RISD staff work with schools to coordinate schedules and support services.

#### **AUDITORY-ORAL EDUCATION**

RISD works with the Rhode Island Department of Education, West Bay Collaboration, and participating school departments to offer an auditory-oral education option in a public school setting for children with cochlear implants or amplification whose families choose to use listening and speaking as their child's communication and learning method. For each child, the IEP process determines whether this option is appropriate.

#### **AFTER HIGH SCHOOL**

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It is important to talk with your child about plans for the future when he or she starts high school. Exploring career or higher education options early will help your child prepare for his or her transition to independence and adult life. Planning for the transition from school to adult life becomes a central part of your child's IEP beginning at age 14. The goal is for your child to become as independent as possible. Your child should take part in the planning, because his or her input will help make the plan more successful.

#### **HIGHER EDUCATION**

Colleges and other institutes for higher learning can provide your child with more career choices and a better future. When researching these places, it is important to find out how they accommodate students who are deaf or hard of hearing with services such as interpreters, note-takers, and tutors.

#### **CAREER OPPORTUNITIES**

There are many resources to help your child learn more about different types of jobs, skill requirements, and job training. These resources include America's Career InfoNet ([www.acinet.org](http://www.acinet.org)) and the U.S. Department of Labor's Occupational Outlook Handbook ([www.bls.gov/oco/home.htm](http://www.bls.gov/oco/home.htm)). The Office of Rehabilitation Services ([www.ors.state.ri.us](http://www.ors.state.ri.us)) and netWORKri ([www.networkri.com](http://www.networkri.com)) are two free agencies that can help your child find a job in the community.



There are no educational, job, or career limitations for your child because he or she is deaf or hard of hearing. For inspirational stories by deaf people who have achieved careers as pilots, doctors, and ministers go to [www.raisingdeafkids.org](http://www.raisingdeafkids.org).

## **YOUR CHILD'S RIGHTS**

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It is important to understand your rights and your child's rights. Families may find that they sometimes disagree with what professionals advise. If you and your family feel you know better alternatives for your child, you have the right to have these considered by the IEP team. Families are their child's best advocate and may need to be persistent in order to get the services needed. Families may have to make phone calls, write letters, attend meetings, and meet with professionals and doctors.

There are a number of measures in place to ensure that children and their families receive appropriate services. These include:

- » A legal way to resolve complaints you have about procedures or services that you or your child receives
- » The right to confidentiality
- » The right to accept or decline services proposed for you and your child
- » The right to examine school or medical records
- » Written prior notice (in your native language) regarding your child's identification, placement, and evaluation
- » The right to use mediation (legal support) to resolve disputes

**The following is a list of federal laws that protect the rights of people who are deaf or hard of hearing.**

### **SECTION 504 OF THE REHABILITATION ACT OF 1973**

This law prohibits discrimination on the basis of a disability in programs and activities that receive federal financial assistance, such as in work and education. Section 504 gives eligible children the right to a free and public education and protects them from discrimination or retaliation in an educational setting. Similarly, Section 504 protects people with disabilities from discrimination in public higher education institutions. For more information, visit the U.S. Department of Education website at [www.ed.gov](http://www.ed.gov).

### **AMERICANS WITH DISABILITIES ACT OF 1990**

The Americans with Disabilities Act (ADA) protects people with disabilities in private sector employment, public services, public accommodation, transportation, and telecommunications.

Under ADA, a person with a disability is one who 1) has a mental or physical impairment that substantially limits that person in a major life activity; 2) has a record of such an impairment; 3) is regarded as having such an impairment.

#### **INDIVIDUALS WITH DISABILITIES EDUCATION IMPROVEMENT ACT OF 2004**

The Individuals with Disabilities Education Act (IDEA) is the federal law that requires that all children be given a free and appropriate public education, with meaningful access to the general curriculum, and high expectations and standards. In 2004, changes were made to IDEA that impact children who are deaf or hard of hearing. The new law is called the Individuals with Disabilities Education Improvement Act of 2004. For more information, visit the U.S. Department of Education website at [www.ed.gov](http://www.ed.gov) or [www.nationalparentcenters.org/index.htm](http://www.nationalparentcenters.org/index.htm).

*IDEA, Part B* refers to the services all states are required to provide to children ages 3 through 21, including access to public education.

*IDEA, Part C* refers to the services all states are required to provide to children from birth to age 3 and their families.

*IDEA, Part D* refers to support provided to states, schools, teachers, and families to improve results for children with disabilities through research, technical assistance, dissemination of information, and other activities that can be most efficiently carried out at the federal level.

#### **WORK INCENTIVES IMPROVEMENT ACT OF 1999**

The Work Incentives Improvement Act of 1999 was designed to remove barriers and provide incentives for people with disabilities to work. This law expands the availability of health care coverage for working people with disabilities and provides such individuals with meaningful opportunities to work.







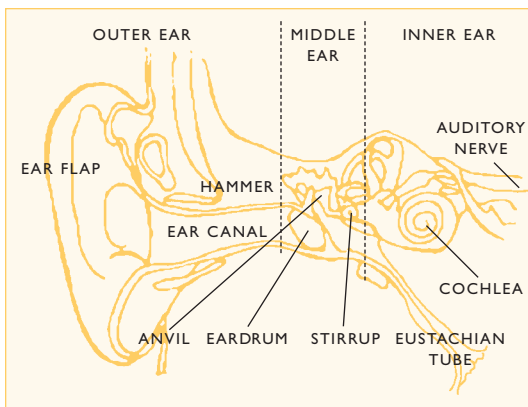
ONE OF THE GREATEST  
DISCOVERIES A MAN MAKES, ONE OF HIS  
GREAT SURPRISES, IS TO FIND HE CAN DO WHAT  
HE WAS AFRAID HE COULDN'T DO.  
~ HENRY FORD

# Causes and Types of Hearing Loss

There are many different causes of hearing loss. Some children may have inherited a hearing loss. Often hearing loss comes from illness, ear infections, or certain medications. However, in some cases, there may be no obvious explanation for hearing loss, and the cause may never be known.

Hearing loss can be a temporary problem caused by a blockage in the outer or middle ear, or it can be caused by nerve damage that will not go away. A hearing loss may even be a combination of these things. How your child's hearing loss will affect his or her language development and growth depends on many things. If the hearing loss can be resolved medically, quick treatment is important. If the hearing loss is permanent, there are many resources

available to support families.



## HOW THE EAR WORKS

Understanding the ear and how it works will help you understand your child's hearing loss and can help you seek the best possible care and services for him or her.

When sounds enter the ear, a chain reaction of vibrations occurs. These vibrations create electrical signals or

messages, which are sent by the nerves in the ear to the brain. Because we have two ears, the difference between sounds entering each ear creates a stereo effect. This helps the brain know where the sounds are coming from and what kinds of sounds they are.

## THE PARTS OF THE EAR

The ear is made up of three parts, which include the outer ear, middle ear, and inner ear.

The outer ear is the part that we see and includes the ear canal. The ear canal is like a tunnel, which ends at the eardrum (or tympanic membrane). Sounds travel through the ear canal and cause the eardrum to vibrate.

The middle ear contains the eardrum and three tiny bones called the hammer (malleus), anvil (incus) and stirrup (stapes). These bones form a small bridge that hangs across a space in the



middle ear. Eardrum vibrations cause the three middle ear bones to vibrate. These vibrations then cause fluid in the inner ear (cochlea) to move.

The inner ear (cochlea) is snail-shaped and filled with fluid. It contains thousands of sensitive hair cells that have tiny hair-like structures at the top of each cell. The movement of the fluid in the inner ear causes the hair-like structures to move. When this occurs, the hair cells create electrical signals that are picked up by the auditory nerve and sent to the brain. The brain interprets these electrical signals as sounds.



## THE ROLE OF GENETICS IN HEARING LOSS

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Genetic testing is optional and may be recommended to help understand the cause of your child's hearing loss. Your child will have a physical exam, and you will be asked about your family history. A doctor, nurse, or technician will take a sample of cells from your child's inner cheek by using a small, soft brush. The sample will be used to check for several gene changes that are known to cause hearing loss. If a gene change is found, you (and any other family members who may be affected) will be offered genetic counseling services. The counselor will explain how genetics could affect you, your child, and other family members. For example, the genetic test may show that the hearing loss may increase over time. This information may help you make decisions now about your child's future.

## RISK FACTORS FOR HEARING LOSS

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Sometimes the cause of hearing loss is known. Other times a cause cannot be identified. However, there are several known "risk factors" for hearing loss. A risk factor is a condition or event that often is connected with hearing loss. Risk factors can sometimes help predict hearing loss in a child, but not always. If your child has a risk factor, he or she will not necessarily have a hearing loss. Also, if your child does not have any risk factors, he or she could still have a hearing loss. Nearly half of all infants with hearing loss do not have any risk factors to explain their hearing loss.

Hearing loss has happened in a high number of children who have the following conditions or risk factors:

- » A family history of childhood hearing loss
- » A mother who had an infection during pregnancy (for example, measles or certain viral infections)
- » Birth defects of the head and neck (such as cleft palate or ear deformities)
- » Low birth weight
- » Extreme yellowing of the skin (jaundice) at birth, requiring a blood transfusion
- » Meningitis
- » Use of certain strong antibiotics to fight infection during the newborn period
- » Use of a respirator for more than five days following birth
- » Apgar scores of less than 4 at 1 minute and/or less than 6 at 5 minutes
- » Exposure to loud noises multiple times
- » Multiple ear infections

## **TYPES AND DEGREES OF HEARING LOSS**

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There are several different types of hearing loss. In addition, there are different degrees of hearing loss that range from minimal to profound. An explanation of each of these types and degrees of hearing loss follows.

### **CONDUCTIVE HEARING LOSS**

Conductive hearing loss is the result of a problem affecting the outer or middle ear. In most cases, conductive hearing loss is not permanent and can be treated either medically or surgically. Common causes of conductive hearing loss include ear infections, excess wax, fluid in the middle ear, or parts of the middle ear that did not form correctly.

### **SENSORINEURAL HEARING LOSS**

Sensorineural hearing loss is the result of a problem in the inner ear affecting the nerve that deals with hearing called the auditory nerve. Sensorineural hearing loss cannot be corrected, but can usually be resolved with the use of hearing aids or cochlear implants. Sensorineural hearing loss usually occurs in both ears, but one ear may be more affected than the other. Common causes of sensorineural hearing loss include a family history of hearing loss, certain medications or infections that the mother had during pregnancy, or other problems around the newborn period (see Risk Factors for Hearing Loss, above).

#### **MIXED HEARING LOSS**

Mixed hearing loss is the result of problems in both the inner ear and the outer or middle ear (sensorineural and conductive hearing loss together). With mixed hearing loss, the conductive loss may be managed with medical treatment, but the sensorineural loss will not go away and may be managed with hearing aids.

#### **UNILATERAL HEARING LOSS**

Hearing loss in only one ear is called unilateral hearing loss. It can be conductive, sensorineural, or mixed. It may be difficult for a child with unilateral hearing loss to know where sounds are coming from and to hear in noisy environments.

#### **PROGRESSIVE HEARING LOSS**

Progressive hearing loss is hearing loss that happens over time. It can be conductive, sensorineural, or mixed. Infants who are able to hear at birth may lose their hearing gradually. In other words, passing the newborn hearing screening does not mean an infant will always have normal hearing.

#### **FLUCTUATING HEARING LOSS**

Fluctuating hearing loss changes often by becoming more or less severe. Sometimes conductive hearing loss can be fluctuating.

#### **SYNDROMIC HEARING LOSS**

Syndromes are groups of symptoms or characteristics that, taken together, identify a certain disease or condition. Some syndromes are associated with hearing loss. If hearing loss is detected early, specialists may be able to test for certain syndromes that may not be identifiable by appearance alone. Two examples of such syndromes are Usher's Syndrome, which is associated with progressive vision loss, and Jervell and Lange-Nielsen Syndrome, which is associated with heart defects.

#### **AUDITORY NEUROPATHY**

Auditory neuropathy is a less common condition in which sound enters the inner ear normally, but the transmission of signals through the auditory nerve from the inner ear to the brain is impaired. People with auditory neuropathy may have normal hearing, or they may have hearing loss ranging from mild to profound. Typically, people with auditory neuropathy have trouble understanding speech clearly, especially if there is a lot of background noise. They may be able to hear sounds but may have difficulty understanding spoken words. Common causes of auditory neuropathy include a family history of hearing loss or health problems at birth, such as mild jaundice or prematurity. Hearing aids are not typically

recommended for children with this type of hearing loss since the transmission of signals to the brain is impaired. An FM system, however, can be of benefit, and in some cases, a cochlear implant may be an option. (See section 4 of this guide, “Sensory Aids,” for more information.)

## AUDIOGRAMS

Hearing test results are often shown on an audiogram. An audiogram is a graph or picture of a person’s hearing. The audiogram will show the degree or severity of hearing loss in each ear. The audiologist will help explain your child’s audiogram to you, so you understand what it says about your child’s hearing. More information about how to read an audiogram is available on the American Academy of Audiology’s website at [www.audiology.org/consumer/guides/uya.php](http://www.audiology.org/consumer/guides/uya.php).

## DEGREES OF HEARING LOSS AND POTENTIAL EFFECTS

The following chart shows the various degrees of hearing loss and the potential effects of the loss. Your child’s audiologist will be able to give you more information about types and degrees of hearing loss.

DEGREE OF HEARING LOSS	POTENTIAL EFFECTS
<b>MINIMAL</b>	» The child may have difficulty hearing quiet or distant speech, especially in noisy places. This can impact speech and language development.
<b>MILD</b>	» The child can hear most speech sounds but is likely to miss parts of words, especially those that contain “s”, “f”, and “th.” This can impact speech and language development. With the proper amplification device, the child is likely to understand all spoken words, even from a distance.
<b>MODERATE</b>	» Without an amplification device, the child may miss 50-100% of speech sounds. This will affect speech development. The proper amplification device should allow the child to hear most sounds at closer distances.
<b>MODERATELY SEVERE</b>	» The child cannot understand words, unless they are very loud. Appropriate services and regular use of an amplification device will determine his or her ability to understand speech and develop language.
<b>SEVERE</b>	» Without amplification, the child may be aware of loud voices near his or her ear. Spoken language will not develop normally without therapy. With an amplification device, the child may be able to hear many sounds of speech and identify environmental sounds, such as car horns.
<b>PROFOUND</b>	» The child is aware of sound vibrations more than actual words. He or she may rely on sight rather than hearing as the primary means of communication and learning. The child’s speech will not develop normally without amplification and therapy.





## EAR INFECTIONS AND HEARING LOSS

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Ear infections, or otitis media, are the most common illness in children and can cause short-term hearing, speech, and language problems. If an ear infection is left untreated, problems can become more serious. Ear infections are usually painful and affect the whole ear, but especially the middle ear.

### **SIGNS OF EAR INFECTIONS**

It is not always easy to know if your child has an ear infection. If your child is not old enough to talk, you may have to look for other signs that there is a problem, such as:

- » Pulling at the ears
- » Crying more than usual
- » Fluid draining from the ears
- » Not reacting to quiet sounds
- » Trouble sleeping
- » Fever
- » Trouble keeping balance

### **WHAT ARE EAR INFECTIONS?**

Ear infections usually happen when viruses or bacteria get inside the ear. They often happen as a result of another illness, such as a cold. It is harder for children to fight illness than it is for adults, and this is a reason why they develop ear infections more often.

When a child has a cold, the eustachian tubes, which are located inside the ear, can become swollen, inflamed, and clogged with fluid and mucus. If the fluids plug the openings of the eustachian tubes, air and fluid get trapped inside the middle ear.

Adenoids are groups of cells that fight infections and are located in the throat, at the base of the eustachian tubes. Adenoids can become infected and swollen and can also block the openings of the eustachian tubes, trapping air and fluid.

#### **DIFFERENT TYPES OF EAR INFECTIONS**

There are two main types of ear infections, called acute otitis media and otitis media with effusion. Acute otitis media happens when the middle ear is infected and swollen, and fluid is trapped inside the ear. Otitis media with effusion can happen when clear fluid remains in the ear after the initial infection is over.

#### **TREATMENTS FOR EAR INFECTIONS**

When there is an acute otitis media, your child's doctor may prescribe an antibiotic drug and sometimes a pain reliever. The antibiotic should be taken until the end of the prescription period. Most health care providers will schedule a follow-up visit to check to see if the infection is gone. Because there are many bacteria that can cause ear infections, some infections cannot be cured with just one antibiotic. As a result, your child may have to try several different antibiotics to cure the infection. After the infection goes away, fluid may remain in the middle ear for several months, but it often disappears after three to six weeks.

If the fluid remains for more than three months and is connected with hearing loss, many health care providers suggest putting tubes in the infected ears in order to drain the fluid. This operation is usually done on by an Ear, Nose, and Throat (ENT) doctor. While the child is asleep under general anesthesia, a small metal or plastic tube is placed in the eardrum. The tube helps dry out the middle ear and keeps the air pressure in the middle ear even. The tubes normally stay in the eardrums for six to twelve months and usually come out on their own. Your child's hearing should return to normal once the fluid is removed with the tubes. Some children may need to have the operation again if the ear infection comes back.





# Sensory Aids

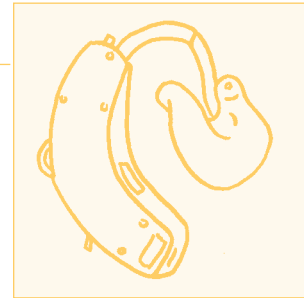
**A PARENT  
UNDERSTANDS WHAT  
A CHILD DOES NOT SAY  
~ ANONYMOUS**

Sensory aids are designed to resolve some types of hearing loss in order to help a child with oral language development. Sensory aids cannot fix hearing loss like glasses fix vision impairments, so your child may also need some special services and programs, such as Early Intervention, the Family Guidance Program, and Special Education. Your child's audiologist can give you more information about these programs and services.

There are three main types of sensory aids your family may want to consider in managing your child's hearing loss: hearing aids, cochlear implants, and FM Systems.

## HEARING AIDS

A hearing aid is a battery-operated device that amplifies (increases) sound. A hearing aid can best help most sensorineural hearing loss and some types of conductive hearing loss.



The selection of a hearing aid is one of the first important decisions that a family may have to make. In recommending a hearing aid, the audiologist will consider factors such as your child's degree of hearing loss, the hearing aid's function, and what types of special hearing technology will be used in your child's school.

Hearing aids have improved greatly over the years and are constantly becoming more advanced in their technology. Many hearing aids today have special microphones and amplifiers, and some even have small computers inside them. These advances in technology affect how hearing aids work. Your child's audiologist will discuss which technology will work best for your child's specific hearing loss. Hearing aids are also now available in many different colors.

## HOW HEARING AIDS WORK

Hearing aids receive sound through a microphone and send the sound to the ear through a speaker. All hearing aids, regardless of style, are made with the same basic parts. These include a microphone, tone hook, earmold, volume control, on/off switch, and battery compartment.

The microphone picks up sounds outside the body and sends them to a processor that makes sounds louder.



The tone hook is a small plastic piece that hooks over and behind the child's outer ear. Your child's audiologist will adjust the hearing aid's tone hook to amplify some pitches of incoming sound more than others. The amplified sound is carried to the earmold through the tone hook.

The earmold holds the hearing aid in the child's ear and directs sound into the ear canal. The earmold fits the shape of your child's ear and stops sound from coming back out of the ear. Over time, it will need to be replaced because the shape of your child's ear will change with age. Also, the plastic can shrink or harden with time.

#### **TYPES OF HEARING AIDS**

There are several types of hearing aids, and each offers different advantages. For more information and pictures of the different types of hearing aids go to [www.hearingaidhelp.com/hearingaids.html](http://www.hearingaidhelp.com/hearingaids.html).

*Behind the Ear (BTE) Hearing Aids* are used for all types of hearing loss. A BTE hearing aid has all of its parts in a curved plastic case that fits behind the ear. Amplified sound comes out of the case and into a clear plastic tube, which goes through the earmold into the ear canal. This type of hearing aid can also work with other devices such as an FM assistive device through a telecoil. A telecoil is a small magnetic coil contained in the hearing aid that improves sound during telephone calls.

*In the Ear (ITE) Hearing Aids* are used for mild to severe hearing loss. ITE hearing aids fit in the ear canal and outer ear. The case, which holds the parts that make up the hearing aid, is made of hard plastic. They have to be replaced often because young children's ear canals grow quickly during the first few years of life. ITE hearing aids may or may not have a telecoil.

*Canal Aids* are used for mild to moderately severe hearing loss. These aids fit into the ear canal. They are available in two sizes: In the Canal (ITC) and Completely in the Canal (CIC). The ITC hearing aid is made to fit the size and shape of the ear. The CIC hearing aid is mostly hidden in the ear canal. Because of the small size of canal aids, these aids may be difficult to adjust and remove.

#### **FITTING HEARING AIDS**

Fitting a child with a hearing aid is different than fitting an adult, so it is important to work with an audiologist who has pediatric expertise. Unlike adults, young children aren't able to say how well the hearing aids are working. It is very important that your child has the best hearing aid possible while his or her speech and oral language skills are developing.

Hearing aids must be fit individually for each child. Even if your child has different degrees of hearing loss in each ear, your child's audiologist will almost always recommend hearing aids for both ears. Two hearing aids are needed to support the child's language and speech development.

The audiologist will show you how to put your child's hearing aids on and how to take care of them. Also, the audiologist will teach your child how to pay attention to and identify sounds. This is necessary because the sounds your child will hear with the hearing aids will be different from what he or she hears without them. It will take practice for your child to recognize familiar and new sounds. This process may require several visits with the audiologist.

#### TESTING THE HEARING AIDS

The audiologist will test the hearing aids while your child is wearing them to determine the best setting. The most important goal for the audiologist is to make speech loud enough for your child to hear.

After the testing is completed, the audiologist will discuss how your child's hearing will be affected by the hearing aids, and what the family can expect as the child gets used to them. Your child may need several more appointments with the audiologist to make sure that the hearing aids are working properly.

#### *Real-Ear-to-Coupler-Difference*

For children under six months of age, a special probe microphone technique called Real-Ear-to-Coupler-Difference (RECD) can be used to test a hearing aid. During this test, a small, soft microphone is placed in the child's ear next to the earmold to allow the audiologist to

THE FOLLOWING CLEANING AND CARE TIPS WILL HELP KEEP YOUR CHILD'S HEARING AIDS AND BATTERIES WORKING PROPERLY.	
HEARING AIDS:	IF THE HEARING AID IS NOT WORKING PROPERLY, CHECK TO SEE IF:
Protect hearing aids by keeping them dry	Battery is dead
Keep hearing aids away from heat and chemicals	Battery is in the right position and the battery door is closed
Clean the earmolds and hearing aids with a dry tissue	Earmold opening is free of wax
Do not use any chemicals on the earmolds or hearing aids	Plastic tubing is not bent or twisted
Put the hearing aids in the case or special moisture removal kit when not in use	Hearing aid is in the "on" position
Be careful not to bend the plastic tubes or wires	If the hearing aid still does not work, do not try to fix it yourself. Take it to your child's audiologist.
Remove hearing aids when bathing or swimming	
Take the hearing aids off at bedtime	
Keep the hearing aids out of the reach of pets	
BATTERIES:	HERE ARE SOME TIPS FOR CARING FOR A HEARING AID'S BATTERIES:
Hearing aid batteries last for approximately one to two weeks depending on the type of hearing aid and how long your child wears it each day. Batteries can be purchased at audiology clinics, drug stores, grocery stores, and department stores.	Remove the battery when the hearing aid is not in use
	To test the battery, use a hearing aid battery tester
	Do not remove the paper tag on the battery until ready to use
	Keep extra batteries on hand and store in a cool, dry place

determine how much sound is delivered to the child's ear. The audiologist uses RECD measures before fitting the hearing aid directly on the child to avoid the problem of too much sound from the hearing aid or inaccurate volume settings. RECD testing is one of the most recent developments in hearing aid evaluation for young children.

#### *Probe Microphone Test*

For young children, the best method of hearing aid testing is called probe microphone testing. Similar to the RECD test, a small, soft microphone is placed next to the ear mold to measure the amount of sound that is carried to the child's ears. Probe microphone measures allow the audiologist to determine how much speech will be heard with different types of hearing aids. It also can be used to compare aided and unaided hearing, different hearing aid settings, and different listening conditions. Because young children have much smaller ear canals than adults, it is important to take these measures to avoid discomfort and further damage to the child's hearing.

#### **PAYMENT AND INSURANCE FOR HEARING AIDS**

The audiologist or Early Intervention Program can provide you with information regarding payment and insurance for your child's hearing aids. If you have health insurance, it will be accessed for payment first. Your health insurance may cover lost or damaged hearing aids. Insurance policies vary, so check with your health insurance company for coverage guidelines. Hearing aids come with one-year standard warranties. As insurance companies do not typically pay for additional warranties, you can purchase extended warranties through companies that specialize in hearing aid insurance or sometimes through the hearing aid manufacturer.

There may be assistance available to help you pay for hearing aids. For children who do not have insurance or whose insurance does not cover hearing aids, Shriners of Rhode Island Charities Trust can help cover the costs of hearing aids, earmolds, and repairs every 3 years until the child is 18 (see section 9 of this guide, "Local Resources," for contact information).

A law was passed in Rhode Island, requiring private insurance companies to cover the cost of hearing aids up to \$400 per aid every 3 years. However, this law does not apply to state employees, companies with fewer than 50 employees, and companies whose insurance company is not based in Rhode Island.

#### **COCHLEAR IMPLANTS**

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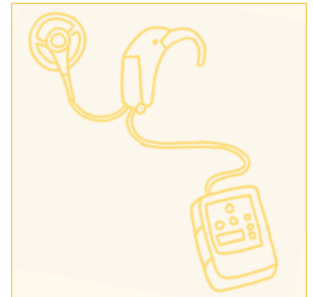
For some families of children with hearing loss, hearing aids may not be the answer. Parents may have to decide whether to choose cochlear implant surgery for their child. Before making this decision, it is important for the family to gather as much information as possible.

#### **WHAT ARE COCHLEAR IMPLANTS?**

A cochlear (coke-lee-ar) implant is an electronic hearing device that helps people with severe to profound hearing loss who get little or no benefit from hearing aids. A cochlear implant may work better than a hearing aid because it bypasses the damaged cochlea and directly stimulates the auditory nerve, which sends sound signals to the brain.



A cochlear implant is made up of outer and inner parts. The outer parts include a microphone, sound processor, transmitter, transmitting cable, and battery. The inner parts, which are surgically implanted, include a receiver and tiny electrodes. The receiver is placed under the skin behind the ear, and the electrodes are inserted into the cochlea in the inner ear.



Surgery requires general anesthesia and takes about two to three hours. The outer parts of the implant are fitted four to six weeks after the surgery when healing is complete.

#### **HOW DO COCHLEAR IMPLANTS WORK?**

A cochlear implant works like an electronic substitute for the cochlea. The device picks up sounds through the outer parts and sends the signals to the inner parts to stimulate the auditory nerve. The process happens so fast that the listener will hear speech and other sounds without any noticeable delay.

Cochlear implants provide improved sound to children with severe to profound hearing loss. Intensive follow-up therapy is required to help your child understand the many new sounds that are heard with the implant.

A cochlear implant destroys all residual hearing in the ear. Residual hearing is the remaining hearing used by a person with hearing loss.

#### **WHO IS A CANDIDATE FOR COCHLEAR IMPLANTS?**

- » Children who have had a hearing aid for at least 3 to 6 months
- » Children aged 12 months and older\*
- » Children with severe to profound hearing loss
- » Children who do not benefit from hearing aids

\*Note: If an infant has had meningitis, the physician may recommend cochlear implant surgery before he or she reaches 12 months of age or before the 3 to 6 month hearing aid trial period is complete. This is because after a meningitis infection, a bony growth can grow over the cochlea, which could make the surgical implantation difficult.



## **PRE-SURGERY EVALUATION AND COUNSELING**

As part of the cochlear implant process, a pre-implant evaluation is necessary. This evaluation may include the following:

*Audiological Evaluation:* An audiologist will measure your child's hearing levels to determine whether an implant or another type of high-powered hearing aid would be best for your child.

*Medical Evaluation:* An ear surgeon will determine if your child can safely undergo general anesthesia and review X rays or a CT scan to ensure that the cochleas are suitable for the implant. The doctor will also look for any other medical conditions that would affect the use of the implant.

*Cochlear Implant Orientation:* The purpose of this conversation is to teach the family about the cochlear implantation process. Audiologists and doctors will discuss the following topics with you:

- » What a cochlear implant is and how it works
- » What kinds of benefits you can expect from the implant
- » Cost of the implant
- » Warranties and insurance for the implant
- » What happens during and after surgery
- » Follow-up schedules

*Expectation Discussion:* This discussion is to make sure the family understands the benefits and limitations of cochlear implants.

*Psychosocial Evaluation:* This evaluation looks at other factors that can influence the adjustment to, or benefit from, the implant. A specialist meets with the family to make sure that they are highly motivated and willing to participate in a long-term rehabilitation program. In addition, the doctor may test your child's learning abilities to rule out other factors that could be responsible for poor hearing and speech-language skills.

## **IMPLANT FOLLOW-UP PROGRAM**

The family of a child receiving a cochlear implant needs to be committed to the program that follows surgery. Your child's cochlear implant team will design a follow-up program so your child can get the most benefit from the implant. The follow-up program may include the following services:

- » Technical Assistance
- » Medical Check-ups
- » Speech Processor Reprogramming
- » Speech and Language Therapy
- » Educational Guidance and Support





# Assistive Devices: Building Independence

As your child grows and experiences new situations, the goals that you have for his or her future will begin to focus on promoting independence. Many assistive devices are available to increase independence during different stages of childhood and the transition to adulthood.

**ABILITY IS WHAT YOU'RE  
CAPABLE OF DOING. MOTIVATION  
DETERMINES WHAT YOU DO. ATTITUDE  
DETERMINES HOW WELL YOU DO IT.  
~ LOU HOLTZ**

## CLASSROOM TECHNOLOGY

### **COMPUTER ASSISTED NOTE TAKING (C-PRINT)**

A captionist (person specially trained to type very fast and accurately) types the lesson notes on a laptop computer on-site in the classroom. The typed notes are shown on a computer or television screen for the student to read. The student receives a typed copy of the notes.

### **COMPUTER ASSISTED REAL-TIME TRANSCRIPTION (CART)**

A trained typist records every word in the lesson (exactly as the teacher says) using special equipment on-site in the classroom. The student reads the words on a television screen and receives a printout of the lesson.

### **VIABLE REAL-TIME TRANSCRIPTION (VRT)**

VRT is different from C-print and CART because the trained typist who records the teacher's words works in an off-site location, not in the classroom. The teacher's words are transmitted through a microphone, which is connected to a phone line, which is connected to a VRT provider site where there is a trained person who types out the lesson. The text is transmitted via the Internet back to the classroom and is displayed on the student's computer in real-time. Real-time means approximately one to five seconds delayed. A transcript of the lesson is provided to the student within 24 hours. VRT is based on the latest technology and eliminates scheduling and traveling costs for an on-site transcriptionist.

### **FM SYSTEMS**

A frequency modulation (FM) system, also called an auditory trainer, is an Assistive Listening Device (ALD). The basic function of this device is to improve the "signal to noise ratio" so that wanted sounds (or signals) are louder and unwanted sounds (or noises) are less loud.



Traditionally, FM systems have been used to help children overcome problems listening in noisy classrooms. With an FM system, the teacher wears a small microphone and transmitter and the child wears a hearing aid and receiver. The sound is transmitted directly from the teacher to the child.

Many pediatric audiologists also recommend FM systems for use outside the classroom on family outings and field trips or while watching television because background noises, echoes, or distance can make listening difficult.

## TELEPHONES

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### AMPLIFIED TELEPHONES

Even with hearing aids, some children will need extra amplification to use a telephone.

Amplified telephones make the voices on the telephone louder.



### T-SWITCH

A T-switch is a feature on some hearing aids that helps wearers hear better on the telephone. The T-switch allows the wearer to switch between the normal microphone “on” setting to a “T” setting that eliminates background noise so the wearer only hears sounds from the telephone. The “T” setting can also be used with FM systems installed in classrooms, theatres, and auditoriums.

### TELETYPEWRITER (TTY)

Understanding voices on the telephone can be difficult for children with severe hearing loss. A teletypewriter (TTY) is a device that allows people who are deaf, hard of hearing, or speech impaired to have phone conversations using typed messages. As your child learns to read and write, a TTY or wireless messaging system can provide him or her with more independence in communicating with friends and family. A TTY is also known as a telecommunications device for the deaf (TDD).

### TELECOMMUNICATIONS RELAY SERVICE (TRS)

TRS allows people who are deaf, hard of hearing, or speech impaired to communicate through a communications assistant (CA). The CA is a third party on the phone line who uses TTY or speech to relay messages and responses exactly as they are received from the callers. TRS can be reached by dialing 711 on all phones in the United States. The relay service is free. All relay calls are confidential.

There are two options when using TRS: voice carry-over (VCO) and hearing carry-over (HCO). Voice carry-over allows a person with hearing loss to speak directly to another party and then read the response that is typed by the communications assistant using a telephone typewriter. With hearing carry-over, a person with speech impairment uses a telephone typewriter to communicate and the communications assistant verbally relays the message to the other party. These services allow people with communication disorders to communicate with all telephone users.

For more information on telecommunications relay services, please visit the Federal Communications Commission at [http://ftp.fcc.gov/cgb/dro/trs/con\\_trs.html](http://ftp.fcc.gov/cgb/dro/trs/con_trs.html).

#### **VIDEO RELAY SERVICE**

Video Relay Service (VRS) enables people who are deaf or hard of hearing who use American Sign Language (ASL) to communicate with voice telephone users through video equipment, rather than through typed text. The VRS caller, using a television or a computer with a video camera device and high speed Internet connection, contacts a VRS communications assistant (CA), who is a qualified sign language interpreter. They communicate with each other in sign language through a video link. The VRS CA then places a telephone call to the party the VRS user wishes to call. The VRS CA relays the conversation back and forth between the parties – in sign language with the VRS user, and by voice with the called party.

The VRS CA can be reached through the VRS provider's Internet site, or through video equipment attached to a television. Currently, more than a half dozen providers offer VRS. Like all TRS calls, VRS is free to the caller. A voice telephone user can also initiate a VRS call by calling a VRS center.

#### **INTERNET PROTOCOL (IP) RELAY**

Internet Protocol (IP) Relay allows people who have difficulty hearing or speaking to communicate with anyone through an Internet connection. IP Relay is accessed using a computer and the Internet. The first leg of an IP Relay call goes from the caller's computer, or other web-enabled device, to the IP Relay Center via the Internet. The IP Relay Center is usually accessed via a web page. The second leg of the call is from the communications assistant (CA) to the receiving party via voice telephone. The CA can also accept IP relay calls from persons with hard-to-understand speech and repeat the calls in an easily understandable form for the called party. There are no additional costs to consumers for IP Relay beyond a computer or other web-capable device and an Internet connection.

## KEEPING IN TOUCH WITH OTHERS

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### TEXT PAGERS

Since most pagers vibrate and have a screen for messages, they are useful communication tools for people who are deaf or hard of hearing. The vibration means there is a new message, and the message shows up on the pager screen.

### EMAIL

Email is another useful way people who are deaf or hard of hearing can communicate with each other and the community. Wireless email devices are available and are widely used among the deaf and hard of hearing community.

## TECHNOLOGY FOR THE HOME

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### PERSONAL AMPLIFIER

This assistive device connects to a hearing aid and sends sound directly from the television to the hearing aid. The hearing aid must have a direct audio input (DAI) to accommodate this device.

### CLOSED CAPTIONING

Closed captioning enables someone who is deaf or hard of hearing to understand what is being said on television by printing the words on the top or bottom of the television screen. Televisions are made with a closed captioning option already included. A television can be switched to the closed captioning setting at any time.

### ALERTING DEVICES AND TACTILE AIDS

Alerting devices and tactile aids provide visual or vibratory signals to help people who are deaf or hard of hearing improve their ability to communicate within their surroundings.

Special lights that are linked electronically to doorbells, telephones, alarm clocks, or smoke detectors can be used as alerting devices. Wrist vibrators or vibrating beepers and alarms are tactile aids that alert the wearer to speech and other sounds.







# Glossary

## **ACQUIRED HEARING LOSS**

Hearing loss that is not present at birth but develops later in life.

## **AMPLIFICATION**

The use of hearing aids or other electronic devices to increase the loudness of sounds so that they may be more easily heard and understood.

## **AUDIOLOGIST**

Hearing loss specialists who are qualified to prescribe hearing aids if necessary. Audiologists perform testing and help you understand the results.

## **AUDITORY DISCRIMINATION**

The ability to pick up differences in sounds and words.

## **AUDITORY NERVE**

The nerve in the inner ear that leads to the brain. It is responsible for carrying nerve messages, resulting from sound stimulation, to the brain.

## **BILATERAL HEARING LOSS**

A hearing loss of any degree that is in both ears.

## **BILINGUAL/BICULTURAL**

Knowing or being fluent in two languages and comfortable in two cultures. For a person who is deaf, these words refer to someone who can “speak” both American Sign Language and English and is comfortable in both Deaf and Hearing Cultures.

## **BINAURAL**

Hearing with both ears.

## **BINAURAL HEARING AIDS**

Hearing aids worn on both ears.

## **CT SCAN**

Stands for computed tomography and sometimes called a CAT scan. It is a medical procedure.

**DEAF**

Spelled with a small “d,” it refers to the phenomenon of being audiotogically deaf. A child who is audiotogically deaf has a hearing loss so severe that he or she cannot adequately process information through hearing, with or without an amplification device.

Spelled with a capital “D,” it refers to a specific linguistic and cultural identity, namely a person whose primary language is American Sign Language and who identifies with the Deaf community.

**DEAF COMMUNITY**

A group of people who share common interests and a common heritage. They use American Sign Language to communicate and identify as being culturally Deaf.

**DEAF CULTURE**

Traditions, values, beliefs, heritage, social networks, political goals, artistic expressions, attitudes, and language that are particular to Deaf people stemming from a history of shared experiences and common oppressions.

**DECIBEL**

Unit of measure for the loudness of sound. The higher the decibel, the louder the sound.

**DEVELOPMENTAL DELAY**

A delay in the development of certain skills, such as crawling and talking, by an expected age. Hearing loss may impact a child’s language development.

**ENVIRONMENTAL SOUNDS**

All sounds that take place around us, but not including speech sounds.

**FEEDBACK**

The whistling sound made when amplified sound goes back into a microphone. In a hearing aid, feedback can occur when an ear mold does not fit well and the amplified sound goes back into the hearing aid microphone. If feedback continues it should be discussed with the child’s healthcare provider.

**FREQUENCY**

Another word to describe the pitch (or highness or lowness) of a sound.

**GENETIC HEARING LOSS**

Hearing loss that is caused by one of more than several hundred genes that are known to cause hereditary hearing loss (hearing loss passed from parents to their children). About 50-60% of all hearing loss is genetic. The hearing loss can be part of a syndrome (meaning the child has other medical problems) or non-syndromic (meaning the child has no other medical problems).

**HARD OF HEARING**

A hearing loss that can be permanent or changing, which affects a person's ability to detect or understand some sounds including speech. The term "hard of hearing" is preferred by the Deaf and hard of hearing community over the term "hearing impaired" when referring to people who have hearing loss and use remaining hearing to communicate.

**HEARING IMPAIRED**

Clinical or medical term used to describe a child whose hearing is below the normal range. It is not the term generally preferred by people who have a hearing loss.

**HEARING SCREENING**

A hearing evaluation that is designed to identify children who require further audiologic testing.

**HUGGIES**

A device that helps keep hearing aids in place on a child's ear.

**IDEA**

The Individuals with Disabilities Education Act (IDEA) is a federal law that guarantees all children with disabilities access to free and appropriate public education. Children who are deaf or hard of hearing are included in IDEA.

**INTENSITY (OF SOUND)**

The loudness of sound, measured in decibels.

**LANGUAGE**

Structured means by which a group of people communicate. Language can be spoken, written, or signed.

**LISTENING AGE**

The length of time a child has had the chance to listen and learn either through existing hearing or with a hearing aid or another assistive device. A child with a listening age of one year might be just beginning to use words even though his or her chronological age is older.

**MANUAL BABBLING**

The early hand shapes used by infants or toddlers who see sign language in their everyday surroundings. As with speech babbling, early manual babbling may not represent any true signs or words. Later manual babbling may be used as part of a young child's beginning communication.

**MONAURAL**

Hearing with only one ear.

**MONAURAL AMPLIFICATION**

The use of one hearing aid instead of two.

**NATIVE LANGUAGE**

The language spoken in a child's home. This could include ASL.

**PITCH**

Highness or lowness of sound.

**PRE-LINGUAL DEAFNESS**

Hearing loss that is congenital (at birth) or develops before learning a language.

**PROGRESSIVE HEARING LOSS**

Hearing loss that gets worse over time.

**RESIDUAL HEARING**

The remaining hearing used by a person with a hearing loss.

**SIGN LANGUAGE**

Sign language uses the hands, face, and body to express language. There are many sign languages. Some examples are American Sign Language (ASL), Italian Sign Language, and French Sign Language.

**TEACHER OF THE DEAF OR HARD OF HEARING**

A person certified by the State Department of Education to teach the deaf or hard of hearing. Parents should begin talking to these teachers when the child is still an infant because they can help with language development and communication.

**THRESHOLD (OF SOUND)**

The softest level at which sound is heard.

**UNILATERAL HEARING LOSS**

Hearing loss that affects only one ear or one side of the head or body.



# Acronyms

**AAA**

American Academy of Audiology

**AABR**

Automated Auditory Brainstem Response (a type of hearing evaluation)

**ABR**

Auditory Brainstem Response (a type of hearing evaluation)

**ALD**

Assistive Listening Device

**ASDC**

American Society for Deaf Children

**ASHA**

American Speech-Language-Hearing Association

**ASL**

American Sign Language

**ASSR**

Auditory Steady State Evoked Response (a type of hearing test)

**AVI**

Auditory-Verbal International (a non-profit organization)

**BCDC**

Boston Center for Deaf and Hard of Hearing Children

**BTE**

Behind the Ear Hearing Aid

**CA**

Communications Assistant

**CART**

Computer Assisted Real-Time Transcription (an assistive device for the classroom)

**CEDARR**

Comprehensive Evaluation, Diagnosis, Assessment, Referral, Re-Evaluation

**CIC**

Completely in the Canal Hearing Aid

**CMP**

Captioned Media Program

**C-PRINT**

Computer Assisted Note Taking (an assistive device for the classroom)

**DAI**

Direct Audio Input (a hearing aid feature)

**DCYF**

Department of Children, Youth and Families

**DHS**

Department of Human Services

**EI**

Early Intervention

**ENT**

Ear, Nose, and Throat doctor

**EPSDT**

Early and Periodic Screening Diagnosis and Treatment Program

**FGP**

Family Guidance Program

**FM**

Frequency Modulation (a sensory aid system)

**HBTS**

Home-Based Therapeutic Services

**HCO**

Hearing Carry-Over (a relay service option)

**IDEA**

Individuals with Disabilities Education Act

**IEP**

Individualized Education Program

**IFSP**

Individualized Family Service Plan

**IP**

Internet Protocol Relay

**ITC**

In the Canal Hearing Aid

**ITE**

In the Ear Hearing Aid

**NAD**

National Association of the Deaf

**NCHAM**

National Center for Hearing Assessment and Management

**NCSA**

National Cued Speech Association

**OAE**

Otoacoustic Emissions (a type of hearing evaluation)

**PARI**

People Actively Reaching Independence  
(a non-profit organization)

**PASS**

Personal Assistant Services and Supports

**PPEP**

Pediatric Practice Enhancement Project

**RECD**

Real-Ear-to-Coupler-Difference (a type of hearing aid test)

**RIAD**

Rhode Island Association of the Deaf

**RICDHH**

Rhode Island Commission on the Deaf and Hard of Hearing

**RIDE**

Rhode Island Department of Education

**RIHAP**

Rhode Island Hearing Assessment Program

**RIPIN**

Rhode Island Parent Information Network

**RISD**

Rhode Island School for the Deaf

**SHHH**

Self Help for Hard of Hearing People

**SSI**

Supplemental Security Income

**TC**

Total Communication

**TDD**

Telecommunications Device for the Deaf

**TLC**

The Learning Center for Deaf Children

**TRS**

Telecommunications Relay Service

**TTY**

Teletypewriter

**VCO**

Voice Carry-Over (a relay service option)

**VRA**

Visual Reinforcement Audiometry (a type of hearing evaluation)

**VRS**

Video Relay Service

**VRT**

Viable Real-Time Transcription (an assistive device for the classroom)



# Local Resources

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## **ALEXANDER GRAHAM BELL ASSOCIATION FOR THE DEAF, INC. (AG BELL)**

The Rhode Island chapter of AG Bell works to improve educational, professional, and vocational opportunities for people who are deaf or hard of hearing. AG Bell promotes better public understanding of hearing loss in children and adults. AG Bell advocates for using the auditory-oral method of communication in the classroom. Members receive the following publications: Volta Review, Newsounds, and Our Kids Magazine.

80 Ann Drive, East Greenwich, RI 02818-1124

Phone: (401) 886-7755

Website: [www.riagbell.org](http://www.riagbell.org)

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## **ASSISTIVE TECHNOLOGY ACCESS PARTNERSHIP (ATAP)**

ATAP is a statewide partnership of organizations and agencies, each with a targeted assistive technology focus, working together to provide information and improve access to assistive technology for individuals with disabilities. ATAP works closely with other state advocacy projects.

40 Fountain Street, Providence, RI 02903

Phone: (401) 421-7005, (800) 916-8324

TTY: (401) 421-7016

Fax: (401) 222-3574

Website: [www.atap.state.ri.us](http://www.atap.state.ri.us)

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## **BOSTON CENTER FOR DEAF AND HARD OF HEARING CHILDREN (BCDC)**

BCDC is an interdisciplinary clinical and research group within the Department of Otolaryngology and Communication Disorders at Children's Hospital Boston. The clinical team includes specialists in psychology, audiology, education, medicine, speech and language, psychiatry, and communication. BCDC provides comprehensive evaluation and consultative services to deaf and hard of hearing infants, children, and teenagers and their families. BCDC coordinates evaluations, referrals, research, guidance, and information for families.

Children's Hospital Boston

300 Longwood Avenue, LO-301, Boston, MA 02115

Phone: (617) 355-7404

TTY: (617) 355-6603

Fax: (617) 355-6042

Website: [www.childrenshospital.org/](http://www.childrenshospital.org/)



**BRISTOL COMMUNITY COLLEGE**

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Bristol Community College offers classes in American Sign Language.

777 Elsbree Street, Fall River, MA 02720

Phone: (508) 678-2811

Website: [www.bristol.mass.edu](http://www.bristol.mass.edu)

**BROWN UNIVERSITY**

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Brown University offers classes in American Sign Language.

Providence, RI 02912

Phone: (401) 863-1000

Website: [www.brown.edu](http://www.brown.edu)

**CEDARR FAMILY CENTERS OF RHODE ISLAND**

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CEDARR (Comprehensive Evaluation, Diagnosis, Assessment, Referral, Re-Evaluation)

Family Centers offer families information on specific disabilities, clinical expertise, referrals to community supports, and assistance for their children with special health care needs. There are three CEDARR Family Centers in Rhode Island that serve families statewide:

About Families, CEDARR Family Center

203 Concord Street, Suite 335, Pawtucket, RI 02860

Phone: (401) 365-6855

Families First CEDARR Center

Hasbro Children's Hospital

593 Eddy Street, Room 120, Providence, RI 02903

Phone: (401) 444-7703

Solutions CEDARR

134 Thurbers Avenue, Providence, RI 02905

Phone: (401) 461-4351, (800) 640-7283

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**CLARKE SCHOOL FOR THE DEAF, CENTER FOR ORAL EDUCATION**

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Clarke School for the Deaf offers educational assessment, planning, and resources for deaf or hard of hearing children from birth through age 21. Clarke also provides audiological services, including assistive listening devices, and residential and day school for preschool through 8th grade students.

Round Hill Road, North Hampton, MA 01060

Phone: (413) 584-3450

TTY: (413) 584-3450

Fax: (413) 584-8273

Website: [www.clarkeschool.org](http://www.clarkeschool.org)

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**COMMUNITY COLLEGE OF RHODE ISLAND**

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Community College of Rhode Island offers classes in American Sign Language.

400 East Avenue, Warwick, RI 02886

Phone: (401) 825-1000

Website: [www.ccri.edu](http://www.ccri.edu)

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**DUAL SENSORY IMPAIRMENT PROJECT**

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The Dual Sensory Impairment Project gives families who have children with vision or hearing loss resources to make informed choices about their child's health care. Serving children from birth to age 21, the Dual Sensory Impairment Project also offers a free assistive technology and toy lending library. The project staff work with schools and also provide direct family support using parent consultants.

Paul V. Sherlock Center on Disabilities

Rhode Island College

600 Mount Pleasant Avenue, Providence, Rhode Island 02908

Phone: (401) 456-8072

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**EARLY INTERVENTION PROGRAM (EI)**

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Early Intervention is a program for children under three years of age who have developmental delays. There are seven EI providers and eight EI sites in Rhode Island (the Trudeau EI Center has two sites but is considered the same provider). Families can choose the EI provider that best meets their needs and the needs of their children.

#### **LOCAL EI PROVIDER SITES**

Children's Friend and Service

621 Dexter Street, Central Falls, RI 02863

Phone: (401) 729-0008

Fax: (401) 729-0010

Website: [www.cfsri.org](http://www.cfsri.org)

Easter Seals

5 Woodruff Avenue, Narragansett, RI 02882

Phone: (401) 284-1000

Family Resources Community Action

245 Main Street, Woonsocket, RI 02895

Phone: (401) 766-0900

Fax: (401) 766-8737

Website: [www.famresri.org](http://www.famresri.org) (look under "How Can We Help")

Family Service

134 Thurbers Avenue, Providence, RI 02905

Phone: (401) 331-1350

Fax: (401) 766-8737

Website: [www.familyserviceri.org](http://www.familyserviceri.org)

Hasbro Children's Hospital

593 Eddy Street, Providence, RI 02903

Phone: (401) 444-4000

Fax: (401) 444-4181

Website: [www.lifespan.org/partners/hch](http://www.lifespan.org/partners/hch)

J. Arthur Trudeau Memorial Center

Kent County Chapter ARC

250 Commonwealth Avenue, Warwick, RI 02886

Phone: (401) 823-1731

Fax: (401) 823-1849

Website: [www.kentcountyarcc.org](http://www.kentcountyarcc.org)

J. Arthur Trudeau Memorial Center  
South County Early Intervention Program  
140 Point Judith Road, Unit 44, Narragansett, RI 02882  
Phone: (401) 783-6853  
Fax: (401) 783-6846  
Website: [www.kentcountyarc.org](http://www.kentcountyarc.org)

James L. Maher Center  
120 Hillside Avenue, Newport, RI 02840  
Phone: (401) 848-2660  
Fax: (401) 847-9459  
Website: [www.mahercenter.org](http://www.mahercenter.org)

Meeting Street Center  
667 Waterman Avenue, East Providence, RI 02914 (moving in 2006 to Providence)  
Phone: (401) 438-9500  
TTY: (401) 438-3690  
Fax: (401) 438-3760  
Website: [www.meetingstreet.org/matriarch](http://www.meetingstreet.org/matriarch)

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#### **FAMILY GUIDANCE PROGRAM**

The Family Guidance Program at the Rhode Island School for the Deaf is a program for families with children who are deaf or hard of hearing. It provides consultation services from trained professionals in the field of deafness and hearing loss. The Family Guidance Program provides all families with the support, guidance, skills, and information needed to make decisions and advocate for their child. The staff and parents work together to develop programs that are tailored to meet the individual needs of each child and family.

Rhode Island School for the Deaf  
1 Corliss Park, Providence, RI 02908-1795  
Phone: (401) 222-3525  
TTY: (401) 222-3888  
Fax: (401) 222-6998  
Websites: [www.rideaf.net/parents/ei.shtml](http://www.rideaf.net/parents/ei.shtml) and  
[www.health.ri.gov/family/hearing/guidance.php](http://www.health.ri.gov/family/hearing/guidance.php)



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**FAMILY HEALTH INFORMATION LINE**

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The Family Health Information Line at the Rhode Island Department of Health is a toll-free service providing answers to questions and referrals to programs and services that improve the health of families. Available to callers from Rhode Island in English and Spanish, Monday-Friday from 8:30am to 4:30pm.

Phone: (800) 942-7434

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**FAMILY VOICES AT RHODE ISLAND PARENT INFORMATION NETWORK**

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Family Voices offers information and education about ways to improve healthcare for children with disabilities and chronic conditions. The Family Voices network includes families, coordinators in each state and region, and a national staff. Members of the network serve on local, state, and national boards and task forces; as staff for state health agencies or parent organizations; and as advisors to private and public health systems and research projects. Their mission is to bring the family perspective into policy discussions and decisions.

175 Main Street, Pawtucket, RI 02860

Phone: (401) 727-4144

TTY: (401) 727-4151

Fax: (401) 727-4040

Website: [www.ripin.org](http://www.ripin.org)

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**FREQUENT FLYERS**

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Frequent Flyers is a service for children with special health care needs and their families that makes hospital admissions easier for children who are admitted often. Any child who is a frequent user of a Lifespan hospital (Rhode Island Hospital, Hasbro Children's Hospital, Miriam Hospital, Bradley Hospital, and Newport Hospital) can become a frequent flyer.

Family Center at Hasbro Children's Hospital

593 Eddy Street, Providence, RI 02903

Phone: (401) 444- 3201

Website: [www.lifespan.org](http://www.lifespan.org)

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**GOVERNOR'S COMMISSION ON DISABILITIES**

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The Commission's goal is to ensure that all people with disabilities are given the opportunities to exercise their rights and responsibilities as Rhode Island citizens and that each person with a disability is able to reach his or her maximum potential in independence, human development, productivity, and self-sufficiency. The Commission is responsible for ensuring that state agencies comply with the state and federal disability rights laws. The Commission acts as a mediator in solving disability discrimination complaints and explores options for resolving the complaint.

John O. Pastore Center  
41 Cherry Dale Court, Cranston, RI 02920-3049  
Phone: (401) 462-0100  
TTY: (401) 462-0101  
Fax: (401) 462-0106  
Website: [www.gcd.state.ri.us](http://www.gcd.state.ri.us)

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**JOHN F. SPELLMAN CENTER**

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The John F. Spellman Center is a private, non-profit organization dedicated to delivering a broad range of training, advocacy, referral, and support services to deaf or hard of hearing residents of Rhode Island.

PO Box 40853, Providence, RI 02940-0853  
Website: [www.riadeaf.org/spellman\\_center.htm](http://www.riadeaf.org/spellman_center.htm)

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**LEARNING CENTER FOR DEAF CHILDREN (TLC)**

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The Learning Center for Deaf Children serves deaf and hard of hearing students from infancy through high school. TLC is comprised of three schools – a comprehensive Parent/Infant through High School program in Framingham, MA; a satellite program in Randolph, MA, which was established in 1994 to better serve the southeastern region; and Walden School, a therapeutic treatment program for deaf students with severe emotional, behavioral, or developmental disturbances.

848 Central Street, Framingham, MA 01701  
Phone: (508) 879-5110  
TTY: (508) 879-5110  
Website: [www.tlcdeaf.org](http://www.tlcdeaf.org)

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**MEETING STREET CENTER**

Meeting Street provides services such as occupational, physical, speech, auditory integration, and sensory integration therapies on an out-patient basis.

667 Waterman Avenue, East Providence, RI 02914 (moving in 2006 to Providence)

Phone: (401) 438-9500

Fax: (401) 438-3760

Website: [www.meetingstreet.org](http://www.meetingstreet.org)

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**MEMORIAL HOSPITAL OF RHODE ISLAND, AUDIOLOGY DEPARTMENT**

The Audiology Department at Memorial Hospital offers hearing aid prescription and fitting, instruction in use and care of hearing aids, communication skills training, and assistive listening devices for telephone, television, and general alert.

111 Brewster St., Pawtucket, RI 02860

Phone: (401) 729-2681

Website: [www.mhri.org/services/services\\_pages/audiology\\_CONTAINER.htm](http://www.mhri.org/services/services_pages/audiology_CONTAINER.htm)

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**NEIGHBORHOOD HEALTH PLAN OF RHODE ISLAND**

Neighborhood Health Plan of Rhode Island offers a specialized care management program for children with special health care needs. Through this program, children with special health care needs, who do not have other health insurance coverage, may be eligible for Medicaid through SSI, Katie Becket, or Adoption Subsidy.

299 Promenade St., Providence, RI 02908

Phone: (401) 459-6000, (800) 963-1001

Fax: (401) 459-6066

Website: [www.nhpri.org](http://www.nhpri.org)

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**OPTIONS FOR WORKING PARENTS**

Options For Working Parents is free service that helps parents find childcare based on the type of care needed, the location of the facility, and any special amenities needed for the child.

Commerce Center

30 Exchange Terrace, Providence, RI 02903

Phone: (401) 272-7510

Website: [www.optionsforworkingparents.com](http://www.optionsforworkingparents.com)

#### **PEDIATRIC PRACTICES ENHANCEMENT PROJECT (PPEP)**

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PPEP is an initiative sponsored by the Rhode Island Departments of Health and Human Services to support primary care pediatric and family practices dedicated to serving children with special healthcare needs and their families. The Pediatric Practice Enhancement Project provides parent consultants from Rhode Island Parent Information Network (RIPIN) in selected practices to help families access information, resources, and community services, including CEDARR. Participating practices include:

Aquidneck Medical Associates  
50 Memorial Boulevard  
Newport, RI 02840  
Phone: (401) 847-2290  
Fax: (401) 847-9533

Dr. Robert Burke  
Memorial Hospital  
111 Brewster Street  
Pawtucket, RI 02860  
Phone: (401) 729-2582  
Fax: (401) 729-2854

Dr. Cheryl Flynn  
2 Wake Robin Road  
Lincoln, RI 02865  
Phone: (401) 333-1656  
Fax: (401) 333-3104

Park Pediatrics  
801 Park Avenue  
Cranston, RI 02910  
Phone: (401) 274-6575  
Fax: (401) 273-2597

Rainbow Pediatrics  
Hasbro Hospital, Lower Level  
593 Eddy Street  
Providence, RI 02903  
Phone: (401) 444-3734, (401) 444-3850  
Fax: (401) 444-7574

South County Pediatric Group  
4979 Tower Hill Road  
Wakefield, RI 02879  
Phone: (401) 789-6492  
Fax: (401) 789-5524

Thundermist Health Center  
450 Clinton Street  
Woonsocket, RI 02895  
Phone: (401) 769-4100  
Fax: (401) 235-6899

Wood River Health Services  
823 Main Street  
Hope Valley, RI 02832  
Phone: (401) 539-0228  
Fax: (401) 539-2663

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**PEOPLE ACTIVELY REACHING INDEPENDENCE (PARI)**

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PARI is a non-profit organization whose mission is to assist people with severe disabilities in gaining independence. PARI also accepts donations of hearing aids and recycles them.

500 Prospect Street, Pawtucket, RI 02860-6259

Phone: (401) 725-1966

TTY: (401) 725-1966

Fax: (401) 725-2104

Website: [www.pari-ilc.org](http://www.pari-ilc.org)

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**PERSPECTIVES CORPORATION**

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Perspectives Corporation is a unique, home-based program designed to provide intensive, therapeutic support services for deaf or hard of hearing children with additional emotional or behavioral health needs.

1130 Ten Rod Road, Building C, Suite 101, North Kingston, RI 02852

Phone: (401) 294-8181

Fax: (401) 294-7773

Website: [www.perspectivescorporation.com/about\\_us.asp](http://www.perspectivescorporation.com/about_us.asp)

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**RHODE ISLAND ASSOCIATION OF THE DEAF (RIAD)**

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The mission of the Rhode Island Association of the Deaf is to advocate for and improve the quality of life for members of Rhode Island's Deaf community. RIAD works to improve awareness, conditions, and opportunities for its members in all aspects of life.

PO Box 40853

Providence, RI 02940-0853

Website: [www.riadeaf.org/index.htm](http://www.riadeaf.org/index.htm)

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**RHODE ISLAND COMMISSION ON THE DEAF AND HARD OF HEARING (RICDHH)**

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The Rhode Island Commission on the Deaf and Hard of Hearing provides information and referrals in response to questions about deafness and hearing loss. The Commission helps deaf or hard of hearing people find interpreters and advocates for equal accessibility to services. The Commission has a lending library of periodicals and videotapes. The Commission also offers sensitivity training on Deafness, such as how to use TTY, cultural differences, emotional challenges, federal and state laws, and more.

1 Capitol Hill, Ground Level, Providence, RI 02908-5850

Phone: (401) 222-1204

TTY: (401) 222-1205

Fax: (401) 222-5736

Website: [www.cdhh.ri.gov](http://www.cdhh.ri.gov)



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**RHODE ISLAND DEPARTMENT OF CHILDREN, YOUTH AND FAMILIES**

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The Rhode Island Department of Children, Youth and Families' Special Needs Adoption Program provides permanent families to children who have experienced significant losses and trauma in their lives. These children may qualify for Adoption Subsidy and Medicaid.

101 Friendship Street, Providence, RI 02903

Phone: (401) 222-5229

Website: [www.dcyf.ri.gov](http://www.dcyf.ri.gov)

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**RHODE ISLAND DEPARTMENT OF EDUCATION (RIDE), OFFICE OF SPECIAL POPULATIONS**

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The Rhode Island Department of Education's Office of Special Populations provides assistance and support to schools and parents in meeting the special education needs of children in Rhode Island. The Office of Special Populations operates a Consumer Complaint program staffed by legal counsel to ensure Special Education programs comply with federal and state regulations.

Shepard Building

255 Westminster Street, Providence, RI 02903

Phone: (401) 222-4600

Fax: (401) 222-6030

Website: [www.ridoe.net](http://www.ridoe.net); IEP Website: [www.ritap.org/IEP](http://www.ritap.org/IEP)

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**RHODE ISLAND DEPARTMENT OF HUMAN SERVICES (DHS)**

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In Rhode Island, the Department of Human Services manages programs and services for children (including children with special health care needs), adults, and families. Programs and services for children with special health care needs include CEDARR, Early intervention, and Medical Assistance.

Center for Child and Family Health

600 New London Avenue, Cranston, RI 02920

Phone: (401) 462-5300, (800) 244-8700, Spanish: (401) 462-1500

TTY: (401) 462-3363

Website: [www.dhs.ri.gov](http://www.dhs.ri.gov)

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**RHODE ISLAND DEVELOPMENTAL DISABILITIES COUNCIL**

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Rhode Island Developmental Disabilities Council promotes creative ways for men, women, and children with disabilities to live more independent, fulfilling lives.

400 Bald Hill Road, Suite 515, Warwick, RI 02886

Phone: (401) 737-1238

TTY: (401) 737-1238

Fax: (401) 737-3395

Website: [www.riddc.org](http://www.riddc.org)

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**RHODE ISLAND DISABILITY LAW CENTER**

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The mission of the Rhode Island Disability Law Center is to assist people with differing abilities in their efforts to achieve full inclusion in society and to exercise their civil and human rights.

349 Eddy Street, Providence, RI 02903

Phone: (401) 831-3150, (800) 733-5332

TTY: (401) 831-5335

Fax: (401) 274-5568

Website: [www.ridlc.org](http://www.ridlc.org)

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**RHODE ISLAND HEARING ASSESSMENT PROGRAM (RIHAP)**

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RIHAP coordinates and provides hearing screening for all newborn infants in Rhode Island. If there are concerns about a baby's hearing, referrals to appropriate medical and audiological services are provided to the family.

Women and Infants Hospital

134 Thurbers Avenue, Suite 215, Providence, RI 02905

Phone: (401) 277-3700

TTY: (401) 277-3701

Websites: [www.health.ri.gov/family/hearing/index.php](http://www.health.ri.gov/family/hearing/index.php) and  
[www.womenandinfants.com/body.cfm?id=92&action=detail&ref=46](http://www.womenandinfants.com/body.cfm?id=92&action=detail&ref=46)

#### **RHODE ISLAND HEARING CENTER**

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The Rhode Island Hearing Center at Rhode Island School for the Deaf provides comprehensive audiological evaluations and outreach services for Rhode Island children in preschool through college, free of charge. In addition, the Hearing Center carries out the public mandate to screen the hearing of children in preschool through grade three throughout Rhode Island.

1 Corliss Park, Providence, RI 02908-1795

Phone: (401) 222-7428

TTY: (401) 222-3888

Fax: (401) 222-6998

Website: [www.rideaf.net/services/audiological.shtml](http://www.rideaf.net/services/audiological.shtml)

#### **RI HOSPITAL & HASBRO CHILDREN'S HOSPITAL, AUDIOLOGY & SPEECH LANGUAGE PATHOLOGY**

##### **SERVICES**

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Rhode Island Hospital and Hasbro Children's Hospital offer many audiology and speech language pathology services, including hearing tests, hearing aids, and comprehensive speech, language, and communication assessments.

593 Eddy Street, Providence, RI 02903

Phone: (401) 444-4000

Website: [www.lifespan.org](http://www.lifespan.org)

#### **RHODE ISLAND PARENT INFORMATION NETWORK (RIPIN)**

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RIPIN is a non-profit organization formed by parents and professionals. The goal of this organization is to give parents of children with disabilities information, training, referrals, personalized support, and parent-to-parent networking. RIPIN has a toll free number to call for information and resources for parents of disabled children.

175 Main Street, Pawtucket, RI 02860

Phone: (401) 727-4144, (800) 464-3399

TTY: (401) 727-4151

Fax: (401) 727-4040

Website: [www.ripin.org](http://www.ripin.org)

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**RHODE ISLAND RELAY SERVICE PROVIDED BY HAMILTON RELAY**

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Rhode Island Relay Service enables communications between people using TTY devices and people using regular telephones. Because of the Americans with Disabilities Act, deaf, hard of hearing, and speech disabled people are able to use standard telephones to communicate with friends, businesses, and family with the help of text telephones.

Phone: (800) 745-6575 or 711

TTY: (800) 745-5555

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**RHODE ISLAND SCHOOL FOR THE DEAF (RISD)**

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The Rhode Island School for the Deaf offers a wide range of educational programs to deaf and hard of hearing children (and their families) from birth through high school. RISD's mission is to ensure that every child who is deaf or hard of hearing will become an independent, contributing citizen. The school aims to provide fully accessible and appropriate environments to meet the unique educational, social, linguistic, and communication needs of every child.

1 Corliss Park, Providence, RI 02908-1795

Phone: (401) 222-3525

TTY: (401) 222-3888

Fax: (401) 222-6998

Website: [www.rideaf.net](http://www.rideaf.net)

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**SARGENT REHABILITATION CENTER**

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The Sargent Rehabilitation Center provides outpatient rehabilitation services to people of all ages with functional disabilities caused by accidents, illnesses, or developmental disabilities. The Center provides evaluation and treatment in audiology, speech language pathology, special education, occupational and physical therapy, psychology, social services, and vocational training. The Center also features an assistive listening device center, provides non-commercial advice on hearing aids and other communication systems, and has a mobile unit used to provide hearing screening.

800 Quaker Lane, East Greenwich, RI 02818

Phone: (401) 886-6600

Fax: (401) 886-6632

Website: [www.shhhsargent.org](http://www.shhhsargent.org)

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**SELF HELP FOR HARD OF HEARING PEOPLE (SHHH),**

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**RHODE ISLAND CHAPTER AT THE SARGENT REHABILITATION CENTER**

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The Sargent Rehabilitation Center is a local affiliate of the national SHHH organization dedicated to opening the world of communication for people with hearing loss through information, education, advocacy, and support. The Sargent chapter holds monthly meetings designed for participants to share experiences with each other. Guest speakers are invited to educate members about issues of hearing loss and to promote self-advocacy. The chapter also publishes a monthly newsletter.

800 Quaker Lane, East Greenwich, RI 02818

Phone: (401) 886-6600

Fax: (401) 886-6632

Website: [www.shhhsargent.org](http://www.shhhsargent.org)

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**SHRINERS OF RHODE ISLAND CHARITIES TRUST**

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The Shriners Program provides financial support for the purchase of hearing aids and earmolds for children who are deaf or hard of hearing. Children from birth through 18 years of age who are treated at the Rhode Island Hospital Hearing and Speech Center have access to this program.

Co-op Bldg, 1st Floor, Rm 170.34

2 Dudley Street, Providence, RI 02903

Phone: (401) 444-4757

Website: [www.rishriners.org](http://www.rishriners.org)

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**SOCIAL SECURITY ADMINISTRATION**

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The Social Security Administration manages the Supplemental Security Income (SSI) program, which provides monthly cash benefits to eligible children from birth to age 18 with disabilities. If a child is eligible for SSI because of a disability, then that child is also eligible to receive Medicaid.

380 Westminister Street, Room 318, Providence, RI 02903

Phone: (401) 528-4535, (800) 772-1213

Fax: (401) 528-4698

Website: [www.ssa.gov](http://www.ssa.gov)



#### **TECHACCESS OF RHODE ISLAND**

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TechACCESS of Rhode Island is a private, non-profit resource center that serves people with disabilities who are interested in assistive technology. Information and referral services regarding assistive technology products, funding, and services are provided at no charge. TechACCESS also provides referrals to service providers, vendors, and advocacy services.

110 Jefferson Boulevard, Suite I, Warwick, RI 02888-3854

Phone: (401) 273-1990, (401) 463-0202, (800) 916-8324

TTY: (401) 273-1990, (401) 463-0202

Fax: (401) 463-3433

Website: [www.techaccess-ri.org](http://www.techaccess-ri.org)

#### **VSA ARTS OF RHODE ISLAND**

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VSA Arts of Rhode Island is a statewide non-profit organization providing high quality programs and opportunities for people with disabilities to actively participate in the visual, literary, and performing arts.

500 Prospect Street, Pawtucket, RI 02860

Phone: (401) 725-0247

TTY: (401) 725-0247

Fax: (401) 725-0397

Website: <http://ri-vsaaarts.org>

#### **WOMEN AND INFANT'S HOSPITAL, AUDIOLOGY CLINIC**

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The audiology clinic at Women and Infant's Hospital provides audiology testing and services for infants older than two months. The clinic also provides audiologic services and treatment for children and adults as well as referrals to audiologists in Rhode Island, Connecticut, and Massachusetts.

134 Thurber's Avenue, Suite 215, Providence, Rhode Island 02905

Phone: (401) 453-7751

Website: [www.womenandinfants.org](http://www.womenandinfants.org)

# National Resources

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## **ALEXANDER GRAHAM BELL ASSOCIATION FOR THE DEAF, INC. (AG BELL)**

AG Bell is a national organization interested in improving educational, professional, and vocational opportunities for people who are deaf or hard of hearing. AG Bell promotes better public understanding of hearing loss in children and adults. Members receive the following publications: Volta Review, Newsounds, and Our Kids Magazine. For the Rhode Island chapter, see the listing in Local Resources.

3417 Volta Place, NW, Washington, DC 20007-2778

Phone: (800) 432-7543, (202) 337-5220

TTY: (800) 432-7543, (202) 337-5221

Fax: (202) 337-8314

Website: [www.agbell.org](http://www.agbell.org)

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## **AMERICAN ACADEMY OF AUDIOLOGY (AAA)**

The AAA is a professional organization of individuals dedicated to providing high quality hearing care to the public.

11730 Plaza America Drive, Suite 300, Reston, VA 20190

Phone: (800) 222-2336, (703) 790-8466

TTY: (703) 610-9022

Fax: (703) 790-8631

Website: [www.audiology.org](http://www.audiology.org)

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## **AMERICAN SOCIETY FOR DEAF CHILDREN (ASDC)**

ASDC is a non-profit organization that provides current information, support, and encouragement to parents and families with children who are deaf or hard of hearing. ASDC promotes parent's rights regarding communication choices for their children and promotes quality education to improve children's lives. It provides a positive attitude toward signing and Deaf Culture and publishes a newsletter called The Endeavor.

PO Box 3355, Gettysburg, PA 17325

Phone: (800) 942-2732

TTY: (717) 334-7922

Fax: (717) 334-8808

Website: [www.deafchildren.org](http://www.deafchildren.org)

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**AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION (ASHA)**

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ASHA is the national professional, scientific, and credentialing association for audiologists, speech language pathologists, and speech, language, and hearing scientists.

10801 Rockville Pike, Rockville, MD 20852

Phone: (800) 638-8255

TTY: (800) 498-2071

Website: [www.asha.org](http://www.asha.org)

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**AUDITORY-VERBAL INTERNATIONAL (AVI)**

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AVI is a private, non-profit, international organization serving children with hearing loss, their families, and the professional community. AVI's goal is to increase awareness and understanding of auditory-verbal communication among consumers, professionals, and policymakers.

2121 Eisenhower Avenue, Suite 402, Alexandria, VA 22314

Phone: (703) 739-1049

TTY: (703) 739-0874

Fax: (703) 739-0395

Website: [www.auditory-verbal.org](http://www.auditory-verbal.org)

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**BEGINNINGS FOR PARENTS OF CHILDREN WHO ARE DEAF OR HARD OF HEARING, INC.**

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Beginnings is a non-profit organization that produces materials and videos to help families make choices about communication methods.

P.O. Box 17646, Raleigh, NC 27619

Phone: (919) 850-2746

TTY: (919) 850-2746

Website: [www.ncbegin.org](http://www.ncbegin.org)

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**BOYS TOWN NATIONAL RESEARCH HOSPITAL FOR CHILDHOOD DEAFNESS**

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Boys Town National Research Hospital is a licensed hospital that researches hearing loss and communication disabilities. This institute accepts children from around the world, without regard to race, creed, or financial means, for evaluation, diagnosis, treatment, and remediation of hearing impairment, speech and language disorders, learning disabilities, and related problems in communication. The hospital also operates a summer program for children who are gifted and deaf.

555 North 30th Street, Omaha, NE 68131

Phone: (402) 498-6540, National Hotline (800) 448-3000

TTY: (800) 320-1171, National Hotline (800) 448-1833

Fax: (402) 498-6562

Website: [www.boystownhospital.org](http://www.boystownhospital.org) or <http://babyhearing.org>

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**CAPTIONED MEDIA PROGRAM (CMP)**

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The National Association for the Deaf provides free loans of educational and entertainment open-captioned cd-roms and videos for deaf and hard of hearing people. Parents and teachers may also borrow captioned videos and cd-roms free of charge. Funds for CMP are provided by the U.S. Department of Education.

1447 East Main Street, Spartanburg, SC 29307

Phone: (800) 237-6213

TTY: (800) 237-6819

Fax: (800) 538-5636

Website: [www.cfv.org](http://www.cfv.org)

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**DEAFPRIDE**

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Deafpride is an organization that advocates for the rights of deaf people and their families.

1350 Potomac Avenue, SE, Washington, DC 20003

Phone: (202) 675-6700

#### **FAMILIES FOR HANDS AND VOICES**

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Families for Hands and Voices is a national, parent-driven organization dedicated to non-biased support of families who have children who are deaf or hard of hearing. Activities include outreach events, educational seminars, advocacy and lobbying efforts, a parent-to-parent support network, and a newsletter.

P.O. Box 371926, Denver, CO 80237

Phone: (866) 422-0422

Website: [www.handsandvoices.org](http://www.handsandvoices.org)

#### **GALLAUDET UNIVERSITY, LAURENT CLERC NATIONAL DEAF EDUCATION CENTER**

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Gallaudet University's Laurent Clerc National Deaf Education Center shares the concerns of parents and professionals about the achievement of deaf and hard of hearing students in different learning environments across the country. The Clerc Center has been mandated by Congress to develop, evaluate, and disseminate innovative curricula, instructional techniques and strategies, and materials. The aim of the Clerc Center is to improve the quality of education for deaf and hard of hearing children and youth from birth through age 21.

800 Florida Avenue, NE, Washington, DC 20002

Phone: (202) 651-5031

TTY: (202) 651-5031

Fax: (202) 651-5636

Website: <http://clerccenter.gallaudet.edu>

#### **HEAR NOW**

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Hear Now is a non-profit organization that provides hearing aids to people with limited financial resources. Hear Now accepts hearing aid donations from all over the country. Hear Now is also involved in increasing public awareness of the need for affordable technology for people with hearing loss.

9745 East Hampton Avenue, Suite 300, Denver, CO 80231-4923

Phone: (303) 695-7797, (800) 648-4327

TTY: (800) 648-4327

Fax: (303) 695-7789

Website: [www.sotheworldmayhear.org](http://www.sotheworldmayhear.org)



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**THE HEARING EXCHANGE**

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The Hearing Exchange is an online community where ideas, information, support, and stories related to hearing loss are shared. It contains stories by children with hearing loss and their parents.

P.O. Box 689, Jericho, NY 11753

Phone: (516) 938-5475

Website: [www.hearingexchange.com](http://www.hearingexchange.com)

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**HELEN BEEBE SPEECH AND HEARING CENTER**

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The Helen Beebe Speech and Hearing Center promotes the auditory-verbal philosophy of training children with hearing loss. The Center's facilities and expertise help people pursue auditory-verbal training and provide services to those in need of speech, language, and hearing therapy.

PO Box 969, 220 Commerce Drive, Suite 320, Fort Washington, PA 19034

Phone: (215) 619-9083

Fax: (215) 619-9087

Website: [www.helenbeebe.org](http://www.helenbeebe.org)

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**HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS**

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The national center and its ten regional offices provide diagnostic evaluation, comprehensive vocational and personal adjustment training, and job preparation and placement for people who are deaf-blind.

111 Middle Neck Road, Sands Point, NY 11050

Phone: (516) 944-8900

TTY: (516) 944-8637

Website: [www.hknc.org](http://www.hknc.org)

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**JOHN TRACY CLINIC**

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The John Tracy Clinic is an educational facility offering direct instruction and correspondence courses free of charge to families of children who are deaf (from birth through age six) and who live anywhere in the U.S. or the world.

806 West Adam Boulevard, Los Angeles, CA 90007-2505

Phone: (800) 522-4582, (213) 748-5481

TTY: (213) 474-2924

Fax: (213) 749-1651

Website: [www.jtc.org](http://www.jtc.org)

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**MARION DOWNS NATIONAL CENTER FOR INFANT HEARING**

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The Marion Downs National Center for Infant Hearing provides information on universal newborn hearing screening, assessment, diagnosis, and early intervention.

University of Colorado at Boulder  
Campus Box 409, Boulder, CO 80309  
Phone: (303) 492-6283  
TTY: (303) 492-4124  
Website: [www.colorado.edu/slhs/mdnc](http://www.colorado.edu/slhs/mdnc)

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**MIRACLE EAR CHILDREN'S FOUNDATION**

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Miracle Ear Children's Foundation provides free hearing aids and services to children 16 years old or younger from low-income families.

Miracle-Ear, Inc.  
5000 Cheshire Lane North, Minneapolis, MN 55446  
Phone: (877) 268-4264  
  
Miracle Ear Children's Foundation  
Phone: (800) 234-5422  
Website: [www.miracle-ear.com/resources/children\\_request.asp](http://www.miracle-ear.com/resources/children_request.asp)

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**NATIONAL ASSOCIATION OF THE DEAF (NAD)**

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The National Association of the Deaf is a non-profit consumer organization safeguarding the accessibility and civil rights of people who are deaf or hard of hearing in education, employment, health care, and telecommunications. NAD provides grassroots advocacy and empowerment, deafness related information and publications, legal assistance, policy development, public awareness, and youth leadership development.

814 Thayer Avenue, Silver Springs, MD 20910-4500  
Phone: (301) 587-1788  
TTY: (301) 587-1789  
Fax: (301) 587-1791  
Website: [www.nad.org](http://www.nad.org)

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**NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT (NCHAM)**

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The goal of NCHAM is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.

Utah State University  
2880 Old Main Hill, Logan, UT 84322  
Phone: (435) 797-3584  
Website: [www.infanthearing.org](http://www.infanthearing.org)

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**NATIONAL CUED SPEECH ASSOCIATION (NCSA)**

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NCSA is a non-profit organization that promotes and supports the effective use of cued speech for communication, language acquisition, and literacy. NCSA raises awareness of cued speech and its applications, provides educational services, assists local affiliate chapters, establishes standards for cued speech, and certifies cued speech instructors and transliterators.

23970 Hermitage Road, Cleveland, OH 44122  
Phone: (800) 459-3529  
Website: [www.cuedspeech.org](http://www.cuedspeech.org)

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**SELF HELP FOR HARD OF HEARING PEOPLE, INC. (SHHH)**

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SHHH exists to open the world of communication for people with hearing loss through information, education, advocacy, and support. For the Rhode Island chapter of SHHH, see the Sargent Rehabilitation Center listing in the Local Resources section of this guide.

7910 Woodmont Avenue, Suite 1200, Bethesda, MD 20814  
Phone: (301) 657-2248  
TTY: (301) 657-2249  
Fax: (301) 913-9413  
Website: [www.shhh.org](http://www.shhh.org)

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**U.S. DEPARTMENT OF EDUCATION**

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The U.S. Department of Education's Information Resource Center can provide information on the Department's programs and agenda, registration for satellite events, directory assistance for the Department, referrals to Department specialists or other experts, and answers to frequently asked questions. Spanish speakers are available.

Washington, DC 20202  
Phone: (800) 872-5327 (USA-LEARN), (202) 401-2000  
TTY: (800) 437-0833  
Website: [www.ed.gov](http://www.ed.gov)



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Providence, Rhode Island

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Women and Infants Hospital  
Providence, Rhode Island

Rhode Island Hearing Screening Follow-up Committee  
Providence, Rhode Island

Rhode Island Parent Information Network  
Pawtucket, Rhode Island

Rhode Island School for the Deaf  
Providence, Rhode Island

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Providence, Rhode Island

Some information was adapted from the State of Alaska's Hearing Resource Guide, [www.raisingdeafkids.org](http://www.raisingdeafkids.org), [www.babyhearing.org](http://www.babyhearing.org), and [www.hdhearing.com](http://www.hdhearing.com).



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RHODE ISLAND DEPARTMENT OF HEALTH